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Nocturnal seizure detection: What are the needs and expectations of adults with epilepsy receiving secondary care?

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ABSTRACT

Introduction: Seizure detection devices (SDDs) may lower the risk of sudden unexpected death in epilepsy (SUDEP) and provide reassurance to people with epilepsy and their relatives. We aimed to explore the perspectives of those receiving secondary care on nocturnal SDDs and epilepsy in general.

Materials and methods: We recruited adults with tonic or tonic-clonic seizures who had at least one nocturnal seizure in the preceding year. We used semi-structured interviews and questionnaires to explore their views on SDDs and their experiences of living with epilepsy. None of the participants had any previous experience with SDDs. We analyzed the data using qualitative content analysis.

Results: Eleven participants were included with a nocturnal seizure frequency ranging from once every few weeks to less than once a year. Some participants experienced little burden of disease, whereas others were extremely impaired. Opinions on the perceived benefit of seizure detection varied widely and did not always match the clinical profile. Some participants with high SUDEP risk displayed no interest at all, whereas others with a low risk for unattended seizures displayed a strong interest. Reasons for wanting to use SDDs included providing reassurance, SUDEP prevention, and improving night rest. Reasons for not wanting to use SDDs included not being able to afford it, having to deal with false alarms, not having anyone to act upon the alarms, having a relative that will notice any seizures, not feeling like the epilepsy is severe enough to warrant SDD usage or not trusting the device.

Conclusions: The interest in nocturnal seizure detection varies among participants with low seizure frequencies and does not always match the added value one would expect based on the clinical profile. Further developments should account for the heterogeneity in user groups.

1. Introduction

Around 30% of people with epilepsy continue to have seizures despite using antiseizure medications (ASMs) [1]. Refractory epilepsy is a major risk factor for complications, including sudden unexpected death in epilepsy (SUDEP) [2,3], and can take a large toll on the quality of life of people with epilepsy and their relatives [4,5]. SUDEP has an estimated incidence of 1.3 per 1000 person-years [6], which accounts for 5.2% of all deaths in people with epilepsy of all ages and 36% of all deaths in people 0–15 years old with epilepsy [7]. While the pathophysiological mechanism underlying SUDEP remains incompletely understood, the presence and frequency of generalized or focal to bilateral tonic-clonic seizures (TCS) are the most important risk factors [3]. SUDEP is mostly sleep-related and unwitnessed [2]. SUDEP risk is higher for those who experience nocturnal TCS [8], and particularly for those sleeping alone, yielding a 67-fold increase in the risk of SUDEP [3]. There are some indications that increasing nocturnal supervision may lower this risk [8–10].

SDDs may enhance nocturnal supervision and facilitate timely intervention by a caregiver (e.g., repositioning, administering

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Abbreviations: ASM, antiseizure medication; SUDEP, sudden unexpected death in epilepsy; TCS, tonic-clonic seizures; SDD, seizure detection device; REL, Rotterdamse Epilepsie Vragenlijst; SPSS, Statistical Package for Social Sciences (Statistical software); MEC-U, Medical Research Ethics Committees United; IQR, interquartile range.

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emergency medication, or calling for professional help) [11–15]. SDD usage might also reduce anxiety in people with epilepsy and their relatives and improve quality of life [4,16–18], but this still needs to be studied [4,12,13,16,19]. Several barriers for using SDDs have been expressed by people with epilepsy, such as technical difficulties, false alarms, and being confronted with their epilepsy every day [4,17,18,20,21]. User preferences may differ between participants, and their coping style may critically impact the perceived added value of SDDs. For example, the experienced added value of the NightWatch, a wearable SDD, depended on the amount of assurance it could offer to reduce parental anxiety and the associated protective behavior, as well as resilience to handle the potential extra burden of care due to false alarms or technical problems [22].

There are several commercially available SDDs in the Netherlands [23]. None of them, however, are reimbursed by health care insurers [24]. Secondary epilepsy care in the Netherlands is provided by district hospitals. People with epilepsy who are difficult to diagnose or fail to become seizure-free after treatment with two ASMs are referred to tertiary care facilities, such as specialized epilepsy centers. Most user surveys and SDD trials have been performed in tertiary epilepsy centers or residential care facilities serving people with a high seizure burden and often with comorbid learning disabilities [4,16,17,20,22,25]. We postulated that those receiving secondary care may have contrasting profiles (e.g., a relatively low seizure frequency) and are likely to have different needs and expectations. We therefore set up a qualitative study to explore the needs and expectations of people with epilepsy receiving secondary care with respect to SDDs, while considering their perceptions of their illness.

2. Materials and methods

2.1. Study design

This is a predominantly qualitative study consisting of semi-structured interviews and questionnaires. We aimed to explore the expectations and beliefs of people with epilepsy treated in a secondary care facility with respect to nocturnal seizure detection devices and the factors underlying their readiness to wear them. This study was set up in collaboration with the Tele-Epilepsy Consortium, a Dutch group of epilepsy neurologists and researchers who are involved in the development of the SDD NightWatch. They were not involved in the recruitment of participants, data collection, data analysis, or presentation of the data. There are no financial ties between the authors and the producers of NightWatch.

2.2. Participants

Participants were recruited from the outpatient neurology clinic of the Maasstad Hospital in Rotterdam, the Netherlands, a district hospital offering secondary epilepsy care.

We recruited adult cases (18 years and older) with at least one nocturnal generalized tonic, generalized tonic-clonic (GTCS), or focal to bilateral TCS in the preceding year. We excluded participants who were known to have a learning disability. We offered to hire a professional medical interpreter for those who were not able to communicate in Dutch or English. Participants meeting the inclusion criteria were informed about the study by their treating neurologist or nurse practitioner. If they expressed interest in participating, they were approached by an independent researcher (MvL). After acquiring informed consent, a date, time, and location were set for the study visit. The participants could choose between having the interview at their own home or at the outpatient clinic. By offering an interview at home, we aimed to lower the threshold for participation. It also helped us to get a better sense of the living conditions of the participants, and the participants felt more at ease. We strived to recruit between ten and twenty participants or until saturation was reached (i.e., additional interviews provided no new insights). We tried to select a diverse group of participants in terms of age, gender, cultural and socio-economic background, and seizure frequency. All participants had been informed at least once about SUDEP by their neurologist or nurse practitioner prior to participating [26].

2.3. Study procedures

Participants were interviewed by researcher MvL at their homes or the outpatient clinic. During this interview, three questionnaires were filled in on paper and a semi-structured interview was conducted. The study visits took place between October and November 2022. We allowed relatives to be present during the interview and contribute if desired.

There were three questionnaires to be filled in. The first questionnaire contained general questions on topics such as living situation and seizure frequency. The second questionnaire was a slightly modified version of the Rotterdam Epilepsy Questionnaire (Rotterdamse Epilepsie Vragenlijst 2.0 (REL 2.0)), which contains questions related to disease severity, anti-seizure medication use, and impact of epilepsy on daily life, and is part of standard epilepsy care in our center. The third questionnaire was filled in after the semi-structured interview and contained statements related to nocturnal seizure detection, perceived safety at night, and the influence of epilepsy on sleep, which they were asked to score on a 6-point Likert scale. The aim of these questionnaires was to gain more insight into the situations and beliefs of the individual participants and to complement our qualitative approach with quantitative measures. The sample size was too small to perform statistical analyses.

The interviews were performed according to a semi-structured topic list, which contained topics such as the impact of epilepsy on daily life, what it is like to have nocturnal seizures, perceived safety at night, possible precautions taken, and pre-existing knowledge on the risks of nocturnal seizures and seizure detection. Care was taken to ask open-ended questions. We stimulated the participants to elaborate on their thoughts and feelings. It was acceptable to deviate from the topic list if any other topics came up that were of interest to the participant and/or the researcher. Participants were aware that their data would be handled anonymously and would not be discussed with their treating neurologist or nurse practitioner. After discussing the aforementioned topics, the interviewer gave structured information about SUDEP and nocturnal seizure detection and answered any questions the participants had about this. The NightWatch was used as an example of an SDD [22,27]. The NightWatch is a wearable that is worn on the upper arm and detects major motor seizures during sleep by monitoring heart rate and movement. It is wirelessly connected to a base station that can be placed at a maximum distance of twenty meters or to a telephone module to alert a predefined person who will receive a phone call in case of an alarm. We informed the participants of the functionalities and shared a picture. The interview then continued, focusing on the participants' thoughts and feelings on nocturnal seizure detection and why or why not they thought it would benefit them. The interviews were audio-taped and transcribed.

2.4. Analysis

We performed descriptive statistics on the data from the questionnaires using SPSS (IBM Corp., version 28.0.1.0, 2021).

The transcripts were analyzed using the qualitative data analysis software ATLAS.ti. We used qualitative content analysis [28] to identify common themes in the data. The transcripts were first read in full by researchers MvL, BK, and SMD (BK and SMD are both experienced in qualitative research) in order to familiarize themselves with the data. The coding process was performed by MvL and was supervised by SMD. Any differences in opinion were discussed and resolved by consensus in order to establish researcher triangulation. The codes were then categorized. MvL, SMD, and BK looked at the grouped data and codes to identify underlying themes and patterns.

2.5. Ethical considerations

This study was conducted according to the principles of the Helsinki Declaration. The study protocol was evaluated by the Medical Research Ethics Committees United (MEC-U). All participants provided written informed consent.

3. Results

The treating physicians identified twenty-seven possible participants. On second look, four of them did not match the inclusion criteria (two people did not experience tonic or TCS, two people experienced their last nocturnal seizure more than one year ago), seven declined to participate, and five expressed their interest in the trial but did not respond to further invitations. Therefore, we included eleven participants with a median age of 43 years (interquartile range (IQR) 35–63). Nine out of eleven interviews were performed at the participants' homes, and two were performed at the outpatient clinic. One participant was interviewed in the presence of a professional medical interpreter, and five of the participants had a relative present during the interview. All participants used ASMs. Eight out of eleven participants were prescribed monotherapy. We noted that one participant had stopped taking their medications without consulting a neurologist. The nocturnal seizure frequency ranged from once every few weeks to less than once a year. Some of the participants lived alone ($n = 3$), some lived with a partner ($n = 5$), children ($n = 4$), and/or a parent ($n = 1$). Five out of eleven participants had not pursued any further education beyond high school, and seven were not presently engaged in any full-time or part-time profession or education. Additional background information on the participants is presented in Table 1 and Table 3 in Appendix A. No new themes came up during the last interviews; therefore, saturation was reached.

3.1. What is it like to live with epilepsy?

The participants' experiences of living with epilepsy varied widely. Some felt that their epilepsy was not a large burden.

> Case 10: (...) *to be honest, I do not think [my epilepsy is] all that sensational.*

Recurring motifs were feeling like epilepsy is a part of who you are, being used to it, and making the best of your life despite living with a chronic illness. On the other hand, some participants experienced great physical or mental distress due to their epilepsy. Themes that emerged were having lost confidence in their own bodies, not wanting to adapt their way of living, not being able to be fully independent, and feeling like a burden to others. Some coping mechanisms that were mentioned were making jokes, not trying to think about it at all, letting go of control, and living in the moment. Many participants discussed the unpredictability of epilepsy, the continuous need to be prepared for the possibility of experiencing a seizure, and the uncertainty of whether the seizures will recur or not after a long seizure-free period.

> Case 3: *Well, for two years I had nothing, and eventually, like a ticking time bomb, I ended up having another seizure.*

The median response given to the statement "I feel safe at night" was 5 (IQR 4–5) on a 6-point Likert scale (1 being completely disagree and 6 being completely agree). Some participants expressed their preference for having nocturnal seizures rather than daytime seizures. Reasons for this were being less likely to hurt yourself when you have a seizure in bed, being able to go to sleep right after a seizure, and not causing distress to others that may witness a daytime seizure.

> Case 2: *So when it happened at night, I actually thought it was safer. And more convenient. Having a seizure during the day was scarier for me.*

One participant who lives alone stated that he was more afraid to have a seizure at night, considering nobody would find him until the morning.

> Case 11: *Actually, I think it's scarier to have a seizure at night than during the day, because, you see, at night it just lasts until the morning comes. Because in the night hours, there's nobody who will ask me how I'm doing.*

Table 1
Summary of participant characteristics.

Case	Age (yrs)	Sex	Type of seizures	Estimated average overall seizure frequency	Estimated average nocturnal seizure frequency
1	52	F	FIA, probable FBTC*	Unsure	Less than once a year
2	40	F	FBTC	Weekly, none in last few months	Less than once a year
3	26	M	FBTC	Once every few months	Once every few months
4	19	M	GTCS	Less than once a year	Less than once a year
5	43	F	GTCS	Once every few weeks	Once every few months
6	63	F	FA, FIA, FBTC	Once or twice a month	Once every few weeks
7	71	M	GTCS	Once a year	Once a year
8	63	M	FBTC	Once a year	Once a year
9	45	M	FBTC	Weekly	Once every few weeks
10	35	M	Generalized tonic	Once every few months	Once a year
11	43	M	GTCS	Once every few months	Once a year

F: female; M: male; FIA: focal with impaired awareness; FBTC: focal to bilateral tonic clonic; GTCS: generalized tonic clonic; FA: focal aware.
* woke up with tongue bite.

3.2. Impact of epilepsy

3.2.1. Impact on health

Most of the participants reported physical complications of seizures, such as burns, wounds, broken bones, or a dislocated shoulder. One case suffered from severe permanent shoulder damage and pain, impairing his ability to work and do household chores. Other epilepsy-related physical symptoms that were frequently mentioned include fatigue and impaired memory. Some topics that came up pertaining to mental health included feeling like a burden to the people around you, feeling that everything you are doing to prevent seizures is useless, and feeling like you are being treated like a child by the people around you. One participant experienced severe panic attacks that last for multiple days after each seizure, which at times even resulted in hospitalization. Feelings of depression, despair, anxiety, and worthlessness were brought up in multiple interviews.

> Case 11: *And I have no, no interest in life anymore most of the time. So yeah, sometimes I think, "Why am I alive?" If I look at it that way. In this situation.*

Fears that were mentioned were fears of mundane things such as going on vacation or going outside alone, but also a fear of dying, a fear of leaving your children behind, or a fear of not being able to find a partner and start a family. A lack of understanding by others was reported as a cause of feelings of isolation and frustration:

> Case 6: *There are, of course, enough people who never have to visit a doctor. And they lack a certain connection or a certain empathy. They say, "Wow, that's quite something". Instead, they say "There are worse things".*

The median response given to the statement "I sleep well at night" in the questionnaire was 5 (IQR 4–5) on a 6-point Likert scale. For the statement "I am afraid to have a seizure at night," the median was 3 (IQR 2–6), and for the statement "The possibility of having a seizure at night influences how well I sleep," the median was 3 as well (IQR 2–5). In the interviews, most participants indicated that the quality of their sleep was not influenced by their epilepsy. One participant reflected on a period in the past after having a nocturnal seizure in which he feared going to sleep and only slept during the day:

> Case 3: *Back then, I only slept during the day. Because then there was always someone with me that could keep an eye out, and I did not have to hope that [my relative] would hear me if I would have a seizure at night.*

3.2.2. Impact on daily life

Multiple participants were unable to complete high school or to pursue further education due to their seizures or other problems associated with their epilepsy (poor concentration and psychological comorbidities). Several participants were declared unfit for work due to their epilepsy or a combination of their epilepsy and other medical issues. Various participants were unemployed at the time of the interview, even though they would have been willing to work. One participant had to give up their own business after developing epilepsy.

> Case 3: *I had to stop working, because they did not renew my contract. Because they had no certainty. They said: "We cannot count on you. We do not know when you will be able to come or not."*

Some consequences of epilepsy on social life that were mentioned were related to avoiding triggers such as stress, sleep deprivation, or flashing lights. This included not going to social events, going home early, or not going too far from home. Participants discussed lacking energy or mental capacity for social events for several weeks after a seizure. They also expressed difficulties with planning social events due to the unpredictable nature of their illness:

> Case 9: *Planning can be difficult sometimes. Because you plan something beforehand, and then when he, for example, has had a seizure the day before, then yeah… (…) Then it's not possible to get up and go the next day [laughs].*

3.2.3. Impact on relatives

Witnessing a seizure can be a traumatizing event. Most relatives could vividly recall the first time they saw their loved one have a seizure. Many thought they were having a heart attack, a stroke, or that they were dying.

> Case 7: *I thought you were dying, yeah. The paramedics said, "Go and warn his daughters", and I thought to myself, Oh dear. And I did not know what it was exactly, and I could not wake him up, and I completely panicked.*

A relative of one of the participants was so traumatized after witnessing her partner's seizure that even months later she had daily panic attacks requiring therapy and medication.

Some topics that partners or family members brought up were constantly feeling responsible for watching over your relative in case something happens, being worried about them, and not wanting to leave them alone. Many mentioned that because their relatives developed epilepsy, they have not been able to sleep as well as they used to.

> Case 8: *She sleeps very, very poorly and easily wakes up. Whenever I make a tiny movement in my sleep, she immediately thinks I'm having an epileptic seizure again.*

One participant goes to bed every night around 11 PM. Her relative stays up in the living room until 4 or 5 AM every night, and during that time, checks on her every fifteen minutes. Adjustments that relatives have made to their lives because of their relatives' epilepsy include helping in the household, postponing a vacation, sleeping over more often, and sending text messages more often to check on them. One participant sleeps on the couch in the living room every night with her teenage children next to her, who do not want to leave their mother alone.

3.3. Seizure detection

3.3.1. Previous knowledge of SUDEP and SDDs

When asked about the risks of nocturnal seizures, some of the things that were named were choking on your tongue, not being able to breathe well, or having a cardiac arrhythmia. Most answered that they did not know anything about their SUDEP risk. One participant had two family members who passed away because of SUDEP. Most had not heard of SDDs before.

3.3.2. Precautionary measures

Many participants were taking precautionary measures to ensure their own safety. Some of these measures were preventative by avoiding triggers like stress or sleep deprivation. Other measures were not leaving the house without a little bag with emergency medication and an explanation on how to use it, lying down or warning others when feeling anything that might signal an imminent seizure, always asking a relative to sleep in your room or in your house, and not wearing skirts when going outside to prevent exposing yourself during a seizure. Adjustments that were made in the bedroom were not having sharp objects or glass near the bed, not sleeping next to the heater, or laying a cushion on the ground next to the bed. One participant who lives alone purchased an alarm button bracelet that he wears day and night. When he presses the button, it alerts his relative, who lives half an hour away. He explained that it does not help him much since he is unable to press the button until a while after recovering from a seizure. The last time he had a nocturnal seizure, he was only discovered hours later in the morning. Nevertheless, he still wears the bracelet:

> Case 11: *It is not a measure that is of much use to me, but at least when I wake up and, like those last times, I have broken something, I can alert someone that something like that has happened.*

What he experiences as a more useful precaution is having his relative send him a text message every morning. If he does not reply, his relative comes over to check on him. None of the participants had used an SDD before.

3.3.3. Advantages or reasons to use SDDs

After receiving a structured explanation on nocturnal seizure detection, participants were asked to discuss their feelings on SDDs and how they felt SDDs might be advantageous or disadvantageous to them in their current situation. The main advantages of SDDs that people named were feeling more secure, sleeping better, preventing SUDEP, being able to have more privacy, and reassuring their relatives (Table 2A).

Table 2A
Advantages or reasons for using nocturnal SDDs.

Reassurance for myself
I will be able to sleep better
I will be able to sleep alone
SUDEP prevention
Insight in actual seizure frequency
Somebody will be able to find me and help me earlier, therefore I will not have as much mental distress afterwards
Reassurance for my relative(s)
My relative(s) will sleep better
My relative(s) will have more time to themselves

> Case 5: *Yes, of course, when I use that and I sleep, then yeah… Then I feel safe, and… There's a device, and when something happens, my partner can respond to it, and nothing will go wrong.*

Some participants mentioned not seeing any benefits of SDDs for them at the moment.

3.3.4. Disadvantages or reasons not to use SDDs

The main disadvantages or reasons not to use SDDs included always having someone in your house who should be able to notice your seizures without using seizure detection, not having anyone in the house or neighborhood to act upon an alarm, the costs, having to deal with false alarms, an SDD being uncomfortable to wear, or not thinking your seizures are severe or frequent enough to want to use it (Table 2B). Some participants mentioned not seeing any disadvantages.

> Case 3: *When my mother is lying here, for example, and that device is on… I think I will have more certainty from the warning that the cats will give her when I have a seizure than from the device.*
>
> Case 1: *Unless I would be more affected or know that I would have more seizures, then it might be of some use to me, but now I'm like, yeah, if I've had a seizure, after 5 minutes it's over, and you know, I'll go on with my life.*
>
> Case 10: *If that thing goes off at night, then… She'll shoot right up, and she will not sleep anymore for a week. And when it turns out to be a false alarm, I think she'll immediately say, "Please throw that thing out the window".*

3.3.5. Expectations of using SDDs

Most of the participants who expressed interest in SDDs indicated that if they would have an SDD they would want to use it every night. One participant would only consider using an SDD when his relative is not at home. Some participants expressed their wish that the device would directly warn emergency services (e.g., primary care facility or ambulance service). Places that were proposed as a location for the base station included their own bedroom, the living room if their relative is there, their relative's bedroom, or at a neighbor's house. Some would like to use the mobile phone module so that a relative will be called when a seizure occurs. Participants living alone had contrasting opinions. Some felt that an SDD would be useless as nobody would be able to respond to the alarm. Others expressed that they would like to send a warning to their relative even if they lived far away, as it would be better to receive help late than to not receive help at all. It was also suggested that a relative could call in response to an alarm to check if everything is okay.

Table 2B
Disadvantages or reasons for not using nocturnal SDDs.

Uncomfortable to wear
Too expensive for what it's worth
I cannot afford it
Relative always notice seizures
Pet (dog/cat) will warn relative when I have a seizure
I think I will wake up myself when I have a seizure
False alarms are annoying
False alarms will cause extreme distress in relative
I do not have anyone that lives nearby available to act on it
I do not want to burden someone with it
My relative(s) is/are not always at home
Annoying to have to charge the device
The seizure will occur anyway
My seizures never last long
I do not have seizures frequently
My seizures are not severe
I do not think I'll have any more seizures
If I have any seizures at night, I do not want to know
I do not trust SDDs
It will not give me complete certainty
I will be confronted with my epilepsy every day
My children might wake up
Others in the building might hear it
I will sleep worse

3.3.6. Need for using an SDD

A few participants were interested in trying an SDD; a few were not; a few might like to try it in the future if their situation would change; and one was not sure yet. Among those who expressed interest, there were both people with a lower and a higher SUDEP risk profile (i.e., always sleeping alone, higher seizure frequency). The group of participants who were not interested in SDDs was a mix between lower and higher SUDEP risk profiles as well. The median response to the question "How much do you need a seizure detection system?" on a 6-point Likert scale ranging from absolutely not to very much was 2 (IQR 2–5). All participants with at least a moderate interest in an SDD (Likert scale of 4, 5, or 6) had an overall seizure frequency of at least once a year, were aged under 50 years, and were in financial distress (i.e., at least sometimes unable to pay bills). Those who were not interested in seizure detection indicated that they might be interested if their relative would work irregular shifts, if their seizures would recur, if they would live alone, or if the SDD would be able to prevent a seizure.

Several participants were not willing to spend money on an SDD. When asked how much money they thought a device like the NightWatch would be worth, the amounts mentioned ranged from €150 to €100,000. More than half of the participants were unable to afford the current price of €1,790 [25], but some expressed strong feelings of hope that it would be reimbursed by health care insurance in the future.

3.3.7. Proposed design and functionalities

When asked about ideal SDD design and functionalities, aspects that were mentioned were the device being small, made of a flexible and soft material, and being able to connect it to a base station that is situated further away. Other ideas for seizure detection that were proposed were an adhesive strip worn on the abdomen or arm, a device that is shaped like a smartwatch, a mattress sensor, or a chip implanted in the body. One participant expressed the need for an SDD that will automatically terminate the seizure:

> Case 8: *You have that too for people with heart conditions*, *right*? *They get a shock or something like that. (…) So*, *I get that seizure*, *and somebody presses a button or something*, *because nowadays you can do all that from a distance. And then he says through the device* "*Hey*, *stop it*".

4. Discussion and conclusions

4.1. Discussion of the results

What stands out from this study is the large disparity among participants in terms of the experienced impact of their epilepsy, ranging from hardly ever thinking about it to living in constant fear and barely going outside. The worries and fears that people with epilepsy encounter do not necessarily conform to the concerns that a healthcare provider might have. Some participants with, in the eyes of health care providers, relatively well-regulated epilepsy experienced extreme fears and limitations in their daily lives. On the other hand, some cases that health care providers might be quite worried about (e.g., living or sleeping alone, high nocturnal seizure frequency) were themselves not worried about their epilepsy at all, despite being aware of the risks of nocturnal seizures.

We noted similar disparities in the perceived benefit of seizure detection. Some did not see any benefit at all and would not want to try it out, even if it were free of charge. Others believed this would completely change their lives for the better. Many healthcare providers may assume that seizure detection is most necessary for those with a high seizure frequency who live and/or sleep alone and have someone in the vicinity to act upon alarms. We noticed, however, that not all participants with a high SUDEP risk profile were interested in SDDs, whereas participants with lower SUDEP risk (i.e., always sleeping in bed with a partner or infrequent seizures) could display a strong interest. Arguments for wanting or not wanting to try nocturnal seizure detection varied widely. Many of them would probably not initially have crossed the mind of a healthcare provider. This highlights the importance of engaging with your patients and keeping an open mind when it comes to discussing the possibility of using seizure detection.

Participants mentioned some disadvantages of SDD use that also came up in previous qualitative studies, such as high costs, having to deal with false alarms, having to think about epilepsy more often, and having to deal with possible technical difficulties [4,16,18,20,21]. Large individual differences in the expectations of SDDs have been noted before [16,20,25,29]. What is unique about this study is that it was performed on adults treated in a district hospital with a relatively low seizure frequency, whereas most research on nocturnal seizure detection so far has focused on children and adults in tertiary epilepsy centers. This study found that nocturnal seizure detection may also be of value to a select group of adult people with epilepsy treated in secondary care facilities. There are, however, many factors at play in the decision to use seizure detection, and it remains a decision that is very dependent on individual preferences and circumstances.

4.2. Limitations

A general limitation of qualitative studies is the small sample size, which may limit the generalizability. Maasstad Hospital is situated in an area of Rotterdam that is known for its low socioeconomic status (SES) and cultural diversity [30]. The population that is treated in this hospital can therefore not necessarily be generalized to other populations in the Netherlands or Western Europe in terms of education, financial situation, health literacy, and spiritual and religious perspectives on health. It is, however, especially important to consider the needs of this marginalized group, which is often underrepresented in research. Additional surveys in different populations, cultures, or healthcare systems are needed to reflect the needs of the entire global target group.

Because of the SUDEP risk, people with nocturnal seizures are actively referred to a tertiary epilepsy center if regular treatments fail. Therefore, we identified only a few cases in our hospital that met our selection criteria (at least one nocturnal seizure in the preceding year). Of the 23 eligible people (out of approximately 1000 total people with epilepsy), seven declined to participate, and five did not respond to our invitations. Reasons for not participating might include the lack of any benefit for the participants other than being able to share their stories. Not participating might also be unrelated to the study itself, as we are used to high no-show rates in our epilepsy population with low socioeconomic status. It is possible that those who experience a large burden of disease are keener to participate. While this bias would skew quantitative analysis, we applied qualitative methods until we reached saturation.

4.3. Implications for the future

Several SDDs are available in the Netherlands [23], none of which are covered by healthcare insurance [24]. The NightWatch was used as an example in this study and costs €1,790 [27]. The costs of SDDs were found to be a large barrier for the participants. This problem might be more pronounced in our population than in other populations due to the relatively low socioeconomic status. Further studies on cost-effectiveness are needed, as costs are an important barrier to further implementation of SDDs, and the lack of reimbursement could lead to healthcare disparities [31]. For new technological health developments like SDDs, it is of vital importance to appreciate user perspectives [20]. Some user needs are currently not met by NightWatch or other similar SDDs, including the possibility to directly alert an emergency medical service and the possibility to place the base station further away. Users also preferred smaller, less conspicuous devices [32].

This study exposed the contrasting perspectives of people with epilepsy in district hospitals on seizure detection and on their attitude toward living with epilepsy, but it also brought up other questions. It would be interesting to have a closer look at the discrepancy between the perspectives of patients and physicians regarding SDD usage, as this may help to improve counseling. None of our participants had any previous experience with SDDs. We studied preconceived notions that individuals with epilepsy have about SDD usage. SDD implementation in daily life might be different than expected and lead to new insights. Further research is needed to explore how our target group of adults receiving secondary epilepsy care would experience a trial period with a nocturnal SDD.

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Declaration of Competing Interest

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Appendix A

Table 3
Full overview of participant characteristics.

Case	Age (yrs)	Sex	Years with epilepsy	Type of seizures	Estimated average overall seizure frequency	Estimated average nocturnal seizure frequency	Last nocturnal seizure	Lives in a house with	Sleeps in a room with	Income	Highest level of education	Employment status	Interested in SDD
1	52	F	19	FIA, probable FBTC*	Unsure	Less than once a year	2–3 months ago	With child(ren)	Alone	Sometimes unable to pay bills, sometimes not	Highschool	Unemployed	No
2	40	F	11	FBTC	Weekly, none in last few months	Less than once a year	9 months ago	With child(ren)	Children	Unable to pay bills every month	MBO†	Unemployed	Yes
3	26	M	10	FBTC	Once every few months	Once every few months	4 months ago	Alone (relative sleeps over every day)	Alone	Most of the times able to pay bills	Highschool	Unemployed	No
4	19	M	3	GTCS	Less than once a year	Less than once a year	1 year ago	Parent(s)	Alone	Most of the times able to pay bills	MBO	Fulltime student	Maybe later
5	43	F	27	GTCS	Once every few weeks	Once every few months	2 weeks ago	Partner	Partner	Unable to pay bills every month	Highschool	Unemployed	Yes
6	63	F	31	FA, FIA, FBTC	Once or twice a month	Once every few weeks	1 week ago	Partner	Partner	Able to pay bills every month with money to spare	Highschool	Unemployed	No
7	71	M	1	GTCS	Once a year	Once a year	4 months ago	Alone (partner is there often)	Alone / partner	Able to pay bills every month with money to spare	University	Retired	No
8	63	M	36	FBTC	Once a year	Once a year	11 months ago	Partner	Partner	Able to pay bills every month with not much to spare	Practical vocational training	Part-time job	Maybe
9	45	M	7	FBTC	Weekly	Once every few weeks	2 weeks ago	Partner, child(ren)	Partner	Sometimes unable to pay bills, sometimes not	Highschool	Unemployed	Yes
10	35	M	1	Generalized tonic	Once every few months	Once a year	6 months ago	Partner, child(ren)	Partner	Able to pay bills every month with money to spare	MBO	Fulltime job	Maybe later
11	43	M	4	GTCS	Once every few months	Once a year	3 weeks ago	Alone	Alone	Unable to pay bills every month	HBO‡	Parttime student	Yes

F: female; M: male; FIA: focal with impaired awareness; FBTC: focal to bilateral tonic clonic; GTCS: generalized tonic clonic; FA: focal aware.
* woke up with tongue bite; †MBO: vocational college; ‡HBO: university of applied sciences.

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