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Uncovering the value of autonomic signs and seizure detection in epilepsy care

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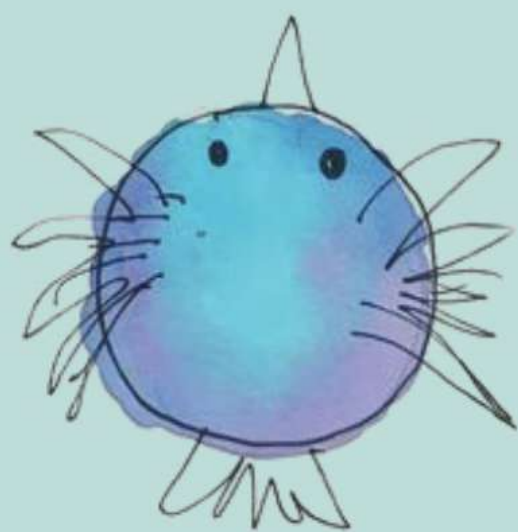
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CHAPTER 8

Parental experiences and perspectives on the value of seizure detection while caring for a child with epilepsy: a qualitative study

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ABSTRACT

Introduction

Caring for a child with epilepsy has a significant impact on parental quality of life. Seizure unpredictability and complications, including sudden unexpected death in epilepsy (SUDEP), may cause high parental stress and increased anxiety. Nocturnal supervision with seizure detection devices may lower SUDEP risk and decrease parental burden of seizure monitoring, but little is known about their added value in family homes.

Methods

We conducted semi-structured in-depth interviews with parents of children with refractory epilepsy participating in the PROMISE trial (NCT03909984) to explore the value of seizure detection in the daily care of their child. Children were aged 4-16 years, treated at a tertiary epilepsy center, had at least one nocturnal major motor seizure per week, and used a wearable seizure detection device (NightWatch) for two months at home. Data were analyzed using inductive thematic analysis.

Results

Twenty-three parents of nineteen children with refractory epilepsy were interviewed. All parents expressed their fear of missing a large seizure and the possible consequences of not intervening in time. Some parents felt the threat of child loss during every seizure, while others thought about it from time to time. The fear could fluctuate over time, mainly associated with fluctuations of seizure frequency. Most parents described how they developed a protective behavior, driven by this fear. The way parents handled the care of their child and experienced the burden of care influenced their perceptions on the added value of NightWatch. The experienced value of NightWatch depended on the amount of assurance it could offer to reduce their fear and the associated protective behavior as well as their resilience to handle the potential extra burden of care, due to false alarms or technical problems.

Conclusions

Healthcare professionals and device companies should be aware of parental protective behavior and the high parental burden of care and develop tailored strategies to optimize seizure detection device care.

INTRODUCTION

Parents* of children with epilepsy are confronted with many complex and demanding caregiving situations. They have to cope with the unpredictability of seizure occurrence, potential complications including hospitalizations, and uncertain long-term outcome. Additionally, their children may experience developmental delays caused by seizures or the underlying brain disorder.¹ Varying degrees of cognitive and physical impairment may coincide with epilepsy, ranging from mild behavioral problems to complete dependency on parental caregiving. Caring for a child with epilepsy is associated with higher rates of parental stress, anxiety, and depression.^{2,3} Parents of children with epilepsy experience compromised quality of life (QoL), influenced mainly by psychological variables (i.e., parental stress response to the child's epilepsy) rather than disease-related ones.^{4,5}

Epileptic seizures may present danger as the result of traumatic falls, injuries and status epilepticus. Yet, the greatest fear of parents caring for a child with epilepsy is the fear of losing their child. Sudden unexpected death in epilepsy (SUDEP) has an estimated incidence of around 1 per 1000 person-years for children < 16 years.⁶ Convulsive seizures, especially if nocturnal and unwitnessed, pose the highest SUDEP risk.⁷⁻⁹ Conversely, SUDEP risk can be decreased by measures to prevent convulsive seizures (e.g., optimizing treatments and encouraging adherence) and also possibly by intensifying nocturnal supervision in those who experience seizures arising from sleep.^{7,10} It is suggested that nocturnal supervision helps to prevent SUDEP by enabling caregivers to intervene.^{7,11} In addition to parental surveillance, seizure detection devices (SDDs) may lead to the recognition of otherwise unwitnessed events and help to improve treatment and reduce SUDEP risk.¹² NightWatch is a wearable SDD assessing heart rate and movement to alarm for nocturnal major motor seizures.¹³ Prospective validation of this device in 28 adults living in a residential care setting showed a median sensitivity of 86% and a median false alarm rate of 0.25 per night.¹³ Devices like NightWatch may enhance parental QoL by decreasing the burden of seizure monitoring.¹⁴ Little is known about the overall burden for parents and how SDDs impact family life. We aimed to explore parent experiences caring for a child with epilepsy and their perspectives on the value of seizure detection in daily care.

* 'Parents' does not only refer to biological parents, but any informal caregiver or legal representative structurally involved in caring for the child with epilepsy.

METHODS

We conducted a qualitative study exploring parent experiences and perspectives on the value of seizure detection while caring for a child with epilepsy in semi-structured interviews, analyzed using inductive thematic analysis.¹⁵ We used the Consolidated Criteria for Reporting Qualitative Studies (COREQ) for our methods and reporting.¹⁶

Sample

This study was part of a more extensive prospective multicenter home-based implementation study: the PROMISE trial (NCT03909984). The PROMISE trial included 60 children with refractory epilepsy for a two-month intervention with nocturnal NightWatch usage in the home environment. LivAssured, the company developing the NightWatch device, provided the devices and equipment used in the study. The company had no role in the study design, analysis, or decision to submit for publication.

Children aged 4-16 years with epilepsy were evaluated for eligibility by their treating pediatric neurologist at three tertiary epilepsy centers in the Netherlands (SEIN, University Medical Center Utrecht and Kempenhaeghe). The children had to live at home and had at least one weekly nocturnal motor seizure. We excluded those with conditions that may generate false alarms such as intense nonepileptic movement patterns, minor motor seizures only (i.e., non-generalized or <10 s), or a pacemaker or cardiac arrhythmias. The Research Ethics Committee of University Medical Center Utrecht approved the study (NL62995.041.17). Between November 2018 and June 2020, we consecutively sampled Dutch-speaking parents who participated in the PROMISE trial and gave informed consent for an interview. We aimed for maximum variation in gender and to include both parents.

Data collection

The semi-structured, in-depth interviews were conducted by two qualified researchers (AvW and WdL). AvW also coordinated the home-based measurements in the PROMISE trial. Neither researcher was involved in the child's treatment.

We extracted background information on children and parents from the PROMISE database. We planned to conduct five pre-intervention interviews focusing on parent expectations of NightWatch and fifteen post-intervention interviews focusing on parent experiences. The interviews were held just before

or immediately after the intervention period to warrant an optimal recall. We conducted the interviews at the parents' home, to create a comfortable environment. During the COVID-19 pandemic, the PROMISE study continued with extra precautions and limited visits. We therefore switched to online interviews for safety reasons. The first interviews were guided by a topic list based on literature and expert knowledge, including the following feasibility items: implementation (i.e., the 'fit' of the device into the care situation of the child), demand (i.e., actual device usage and parental needs for a device), acceptability (i.e., satisfaction about the device), practicality (i.e., the value of the device in caring for the child), and integration (i.e., integration in their family and medical situation).¹⁷ The list was further adjusted throughout the course, guided by the results from the preliminary analysis. The following topics were additionally supplemented: the burden of care, changes in burden and needs over time, and the added value of NightWatch. The exact number of interviews depended on code saturation (i.e., additional interviews do not further change conclusions).^{18, 19}

Data analysis

Interviews were audiotaped with permission, transcribed verbatim, and analyzed using the software program NVivo (QSR International Pty Ltd. Version 12 Pro, 2018). We used an inductive thematic analysis with methods to ensure reliability and validity.^{14, 15, 17-19} The data analysis was supervised by a senior researcher (MK), who read several transcripts to validate the results and guided the coding process. MK is an experienced qualitative researcher at UMCU with expertise in researching parents caring for a child with a life-limiting condition. We analyzed the data in batches of about five interviews. Two researchers (WdL and AvW) read the transcripts thoroughly to get familiar with the data. Subsequently, they identified and coded relevant parts of the data independently, drawing conclusions from what they observed in the complete interview. During joint meetings, all codes were compared, some initial interpretations were reconsidered, and some similar codes were merged, to reach consensus on drawn conclusions, and establish researcher triangulation. Using the constant comparative method, the coded data were continuously compared with newly collected data and grouped to form categories on a more abstract and conceptual level.¹⁵ These categories were checked against new raw data. Code saturation was reached when no new categories or themes emerged from the new raw data. The final themes were used to describe the parent experiences

Table 1A Characteristics of participants: children

Case	Type of caregiver/ sex		Child		Years with epilepsy	Intellectual disability	Epilepsy etiology	Type of seizures	Course of epilepsy ^a
	Age/ Sex	Age/ Sex	Age of onset	Sex					
1	Parent/ F	5/ F	7 months	5/ F	4.5	Yes	Structural	FOIA: FBTC, tonic, atonic and epileptic spasms (multi)FOIA: FBTC, tonic, myoclonic	Stable ^b
2	Parent/ F	10/ M	1 year	10/ M	9	Yes	Structural genetic	FOIA: Tonic-clonic, tonic, atonic and myoclonic	Erratic
3	Legal representative/ F	9/ M	Neonatal	9/ M	9	Yes	Structural, traumatic	FOIA: Tonic-clonic, tonic, atonic and myoclonic	Stable
4	Parent/ F	16/ M	Neonatal	16/ M	16	Yes	Genetic	Generalized tonic-clonic	Stable
5	Parent/ F	7/ M	8 months	7/ M	6.5	Mild	Structural	FOIA: tonic	Stable
6	Legal representative/ F	10/ F	2 years	10/ F	8	Yes	Unknown	Tonic-clonic, tonic, absences	Stable
7	Parents/ F + M	14/ M	2 years	14/ M	12	Yes	Genetic	Generalized tonic-clonic, tonic, atonic, absences	Erratic
8	Parent/ F	13/ F	5 years	13/ F	8	No	Structural	FOIA: Tonic	Stable
9	Parents/ F + M	6/ M	2 years	6/ M	4	Mild	Unknown	Tonic-clonic, atonic	Erratic with cognitive decline
10	Parent/ F	7/ F	5 years	7/ F	2	Yes	Genetic	Generalized tonic-clonic	Stable
11	Parent/ F	12/ F	Neonatal	12/ F	12	Yes	Genetic	Generalized tonic, atonic	Erratic
12	Parent/ M	14/ M	4 years	14/ M	10	Yes	Unknown	FOIA: FBTC	Erratic
13	Parents/ F + M	12/ M	1 year	12/ M	11	Yes	Genetic	Generalized tonic	Stable
14	Parent/ F	6/ F	4 years	6/ F	2	No	Unknown	Generalized tonic-clonic, tonic, absences	Stable
15	Parents/ F + M	11/ M	3 months	11/ M	11	Mild	Structural genetic	FOIA: tonic	Erratic with cognitive decline
16	Parent/ F	10/ M	3 years	10/ M	7	Mild	Unknown	FOIA: FBTC	Stable
17	Parent/ F	10/ F	4 years	10/ F	6	No	Unknown	Tonic-clonic, absences	Erratic
18	Parent/ F	16/ F	14 years	16/ F	2	Yes	Genetic	Generalized tonic-clonic	Erratic
19	Parent/ M	5/ F	3 years	5/ F	2	Yes	Genetic	FOIA: FBTC, tonic, atonic	Stable

F female, FBTC focal to bilateral tonic-clonic, FOIA focal onset with impaired awareness, M male.

^aAs experienced by the caregiver at the moment of the interview.

^bA stable course of epilepsy is defined as a course with a stable seizure frequency, either high or low.

Table 1B Characteristics of participants: caregivers

Case	Respondent		Family composition	Siblings	Educational level respondent 1	Work situation respondent 1
	1: Age/sex	2: Age/sex				
1	36/F		Biological parents	0	Secondary vocational education	Part-time, irregular shifts
2	41/F		Biological parents	2	Secondary vocational education	Unemployed, caring for child
3	40/F		Legal representatives	2	Secondary vocational education	Part-time
4	45/F		Biological parents	3	Secondary vocational education	Part-time
5	40/F		Biological parents	3	Secondary vocational education	Part-time
6	35/F		Single legal representative	1	Secondary vocational education	Part-time
7	57/M	53/F	Biological parents	1	Secondary vocational education	Unemployed, housewife
8	39/F		Biological parents	3	Primary education	Unemployed, housewife
9	47/F	46/M	Biological parents	1	Secondary vocational education	Full-time
10	32/F		Combined family	1	Secondary vocational education	Part-time
11	40/F		Combined family	4	Secondary vocational education	Part-time
12	52/F		Biological parents	2	Secondary vocational education	Both unemployed, parents choose to take care of their children
13	37/F	41/M	Biological parents	1	Secondary vocational education	Part-time
14	34/F		Combined family	2	Secondary vocational education	Part-time
15	42/F	47/M	Biological parents	3	Secondary vocational education	Part-time
16	50/F		Biological parents	2	Secondary vocational education	Part-time
17	41/F		Biological parents	2	Secondary vocational education	Part-time
18	49/F		Single biological parent	1	Secondary vocational education	Part-time
19	44/M		Biological parents	2	Secondary vocational education	Part-time

F female, M: male.

and perspectives on the value of seizure detection while caring for a child with epilepsy.

RESULTS

The parents of 42 of 60 PROMISE participants consented to the semi-structured in-depth interviews. We included 23 respondents: fifteen mothers, six fathers, and two female legal representatives (mean age 43.0 ± 6.4 years) of nineteen cases (Table 1). 21 Interviews were completed, five before and sixteen after the NightWatch intervention, including two repeated interviews and four interviews with both biological parents. The first fourteen interviews took place in the home environment, and the last seven via video calls, due to the COVID-19 pandemic. The children with epilepsy had a mean age of 10.2 ± 3.5 years, had an average epilepsy duration of 7.7 ± 4.2 years, and 63% had severe intellectual disability (Table 1A). In some children the seizure frequency was stable during the intervention ($n = 11$), while others experienced an erratic course ($n = 8$), with increased seizure frequency, and some had a cognitive decline ($n = 2$). For most the two biological parents were present, with an average of two siblings. Some combined families and legal representatives were included. The majority of parents worked part-time. Many had adjusted their work hours to take care of their child, and some had stopped working completely (Table 1B).

The interviews indicated that the fear of losing a child encouraged parents to develop a particular protective behavior. We learned that this behavior helped them reduce fears, yet it could also increase their burden of care. The way parents handled their child's care influenced their perception of the care burden, affecting their fears and protective behavior. The experienced value of NightWatch was dependent on the amount of assurance it could add to their existing protective behavior, and their resilience to handle the potential extra burden of care, due to false alarms or technical problems (Fig. 1).

Fearing child loss

All parents expressed fears of missing a “big”, potentially dangerous seizure and the possible consequences if they could not intervene in time (Table 2, quote 1A). The fear of losing their child was presented to varying degrees; some parents felt the threat at every seizure (Table 2, quote 1B), while others thought about it from time to time (Table 2, quote 1C). Parents also emphasized their anxieties of not being present to help when their child needed them (Table 2, quote 1D). The fear of child loss varies over time and often seemed

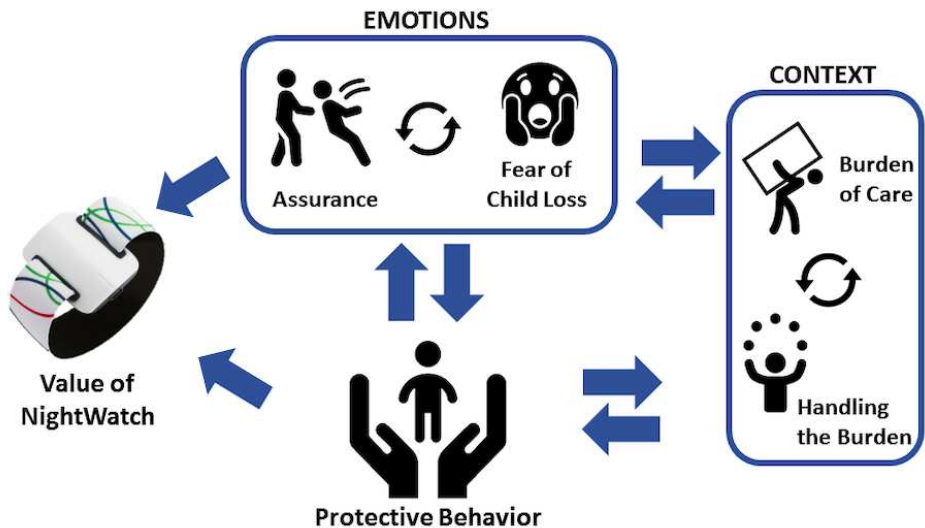


Figure 1 Schematic overview of most important themes describing parental experiences and perspectives on the value of seizure detection while caring for a child with epilepsy.

associated with fluctuations of seizure frequency. A decrease in seizure frequency could ensure that things would get better and lower the level of anxiety. In some cases, this was the other way around; the longer period without a seizure, the more watchful parents got, scared of a seizure soon to happen (Table 2, quote 1E). Some parents, however, were continually aware of potentially risky situations due to the unpredictability of seizures (Table 2, quote 1F). Even a silent night could frighten some parents because it could soon get too quiet (Table 2, quote 1G).

Protecting your child

From the parent stories, it became clear that all parents felt a strong need to protect their child. Most parents emphasized that this need was more significant than toward other siblings (Table 3, quote 2A). Presumably driven by the anxiety of child loss, parents developed specific strategies to protect their child. The goal of this “protective behavior” was to prevent any harm to the child. Almost all parents indicated that they had to keep an eye on their child constantly during the day due to seizures’ unpredictability (Table 3, quote 2B). At night, various measures were taken, from sleeping in the same room as their child, or even in the same bed (Table 3, quote 2C), to sleeping on the couch with a camera (Table 3, quote 2D) and staying awake all night (Table 3,

Table 2 Illustrative quotes for the theme: Fearing child loss + **Table 3** Illustrative quotes for the theme: Protecting your child

Quote	
1A	Case 1: Girl, 5 years, ID. Mother: <i>Well, you see, she usually recovers spontaneously from those small seizures. But I am terrified that one day she will get a big seizure, that gives her breathing problems and that I miss it. That I don't hear her. And then she dies.</i>
1B	Case 15: Boy, 11 years, MID. Mother: <i>The most intensive part is to see my child having a seizure [...] every time I see it, I have a feeling as if I am going to lose him. And that feeling never passes.</i>
1C	Case 3: Boy, 9 years, ID. Legal representative: <i>The risk that you will miss something and it really goes wrong, is of course, out there. And it is not something you reflect on daily, but you think about it from time to time: what if you really miss a seizure and he does not recover spontaneously? I mean, two children died that way at his school....</i>
1D	Case 13: Boy, 12 years, ID. Father: <i>[...] but the last time, it took at least a few hours before he recovered in the hospital. So, imagine that this would have happened at night and we would have missed it. [...] that would have been very difficult.</i>
1E	Case 17: Girl, 10 years, MID. Mother: <i>It remains frightening [...] Especially when she didn't have a seizure for several days, you know it's going to happen soon....</i>
1F	Case 17: Girl, 10 years, MID. Mother: <i>All the time it's in your head: oh girl, where are you? [...] two months ago, she fell backwards from the stairs [...] she just has to pull that pan off the heat... [...] she only has to hit her head on the bathtub....</i>
1G	Case 18: Girl, 16 years, ID. Mother: <i>And when I thought: now she lies very quiet, then I will have a look to see: do I still hear her breathing?</i>
2A	Case 5: Boy, 7 years, MID. Mother: <i>With Tom we are extra attentive. Because he is just a bit different, so we are extra alert. Especially me, being a mother... We are more alert with him, with everything.</i>
2B	Case 17: Girl, 10 years, MID. Mother: <i>The past three months in lockdown were very intense for me. All the time I was listening: "What are you doing? Do I still hear something?"</i>
2C	Case 19: Girl, 5 years, ID. Father: <i>The moment we go to bed, she comes to lie between us and then we put one of our hands on her body, so in case we fall asleep and she has a seizure, we can feel it.</i>
2D	Case 10: Girl, 7 years, ID. Mother: <i>When she has many seizures, I usually don't sleep in my bed. Sophie sleeps downstairs, so I will go lay on the couch with the baby monitor with camera.</i>
2E	Case 8: Girl, 13 years, MID. Mother: <i>I couldn't sleep when she had many seizures, so I stayed here, awake in the living room until 5 am and I slept during the day.</i>
2F	Case 17: Girl, 10 years, MID. Mother: <i>She is sleeping in another room, but since she has the big seizures, we keep the doors open, so we can hear her. I often lie awake in bed to listen: is she still there?</i>
2G	Case 6: Girl, 10 years, ID. Legal representative: <i>I have a video camera on my baby monitor. This is connected to an app on my mobile phone, so I can watch her. When a babysitter is watching her and she has a seizure, and the babysitter is insecure, I can watch from a distance. That gives me a safe feeling.</i>
2H	Case 18: Girl, 16 years, ID. Mother: <i>She constantly needs someone around, not because of her seizures, but because she can't recognise dangerous situations.</i>

ID Intellectual Disability, MID Mild Intellectual Disability, NID No Intellectual Disability.

Some quotes are slightly modified to improve readability. Names are fictitious.

Table 4 Illustrative quotes for the theme: Handling the burden of care

Quote	
3A	Case 10: Girl, 7 years, ID. Mother: <i>It is hard to find a moment for yourself, to reboot, to do fun stuff. That is easily postponed, because you only have time to do the things you must do.</i>
3B	Case 2: Boy, 10 years, ID. Mother: <i>Most of the time I take care of him. I had no night's rest. Sometimes, he had a seizure in the morning, and it didn't feel good to go to work, so eventually I decided to quit my job.</i>
3C	Case 7: Boy, 14 years, ID. Mother: <i>Caring for him is a heavy burden. Everybody asks me: Is it not too heavy? And I answer: if I bring him to daycare five days a week, I will even get worse nights with him, because he can't handle all the commotion over there.</i>
3D	Case 14: Girl, 6 years old, MID. Mother: <i>[...] All sorts of things, personal budget, transportation. Because I take Anne to school myself, this causes a bizarre administrative load as well.</i>
3E	Case 15: Boy, 11 years, MID. Mother: <i>I think the psychological burden is heavier than a disrupted night's rest.</i>
3F	Case 15: Boy, 11 years, MID. Mother: <i>You might think that the feeling wears out if you have seen so many seizures from which he always recovers, but every time it gives me the sense that it is not right [...]. And also the uncertainty: what will this mean for his future?</i>
3G	Case 9: Boy, 6 years, MID. Mother: <i>The worst part is of course, that he is cognitively behind. Very slowly, we see him decline, and that is painful to watch.</i>
3H	Case 7: Boy, 14 years, ID. Father: <i>We notice that the care is getting heavier. So, it will not be possible to keep him at home for a long period. We are both convinced of that. Mother: And we are planning to set up our own house of care. [...]. Because John doesn't fit into a home with six to eight children, he will get way to overstimulated. [...]. He needs one-on-one care, that is really needed.</i>
3I	Case 9: Boy, 6 years, MID. Father: <i>I would like to know everything that is happening during the night. Even if it is exhausting and a burden, I would still like to know what is happening.</i>
3J	Case 17: Girl, 10 years, MID. Mother: <i>There are two sides to the coin: on the one hand, we must continue looking for something that might help her. On the other hand, I should not let it drive me crazy. I cannot let myself go down with it because I am certainly of no use for her.</i>
3K	Case 3: Boy, 9 years, ID. Legal representative: <i>Eventually, you sort of get used to it. If others see or hear what we experience, they think: ... so many seizures. And we think, well... for us this is our reality, so to say.</i>
3L	Case 1: Girl, 5 years, ID. Mother: <i>He (husband) sleeps better than me and I think, as a man, you may experience it differently. He is less bothered by nightly fears, of course he is also scared, but we experience it differently.</i>

ID Intellectual Disability, MID Mild Intellectual Disability, NID No Intellectual Disability. Some quotes are slightly modified to improve readability. Names are fictitious.

quote 2E). Some parents kept the bedroom doors open (Table 3, quote 2F), or installed monitoring devices (e.g., baby monitors with audio and/or camera facilities) in their child's bedroom. Sometimes parents used monitoring devices to watch from a distance when someone else watched their child (Table 3, quote 2G). Parents of children with intellectual disability mentioned that their child's behavior often led to unsafe situations, which demanded extra alertness (Table 3, quote 2H). All these strategies often had a significant impact on the parent night's rest and their whole life.

Handling the care of their child

Parents experienced a significant burden of care, caused by their child's specific needs and amplified by their fear of child loss and their developed protective behavior. This protective behavior often reduced parental anxiety, but it increased their burden of care in many cases. Their protective behavior resulted in constant alertness and broken nights, which significantly impacted their lives. Parents made many adjustments to provide optimal care, from downsizing their social life (Table 4, quote 3A) to quitting their job (Table 4, quote 3B). Some parents stated that they were the only ones that could deliver good care for their child and that it was hard to outsource care (Table 4, quote 3C). Additionally, many parents emphasized the extra burden of organizing all the care regulations (e.g., transportation, special adjustments in the house; Table 4, quote 3D). From the most recent interviews, it became clear that the COVID-19 pandemic aggravated the burden of care as day-care and daily structure for the child were suddenly lost.

Apart from the burden caused by their protective behavior, the anxiety of child loss also strongly affected the parental burden of care. The psychological burden seemed heavier for many parents than the physical one (Table 4, quote 3E). This psychological component also concerned parental struggle with the unpredictability of seizures and the uncertainty about their child's wellbeing in the future (Table 4, quote 3F). Parents of children without intellectual disability were worried about how epilepsy would affect their child's development. Some described that it was painful to watch their child's cognitive decline (Table 4, quote 3G). Conversely, parents of children with severe intellectual disability from a young age were mainly worried about the question of where their child would live if they could no longer keep care at home (Table 4, quote 3H). The way parents handled the care of their child varied greatly and seemed independent of the course of epilepsy (i.e., stable or erratic). In two cases of cognitive decline, however, there was a strong urge for parents to control the

situation. One family tried to regain control by monitoring every aspect of their child's life, even though this increased their burden (Table 4, quote 3I). Other parents stated that they were constantly trying to balance "being there to protect the child" and "keeping yourself standing" because if they let themselves fall, they would be of no use for their child (Table 4, quote 3J). Some parents seemed to be used to the situation on the other end of the spectrum and explained that they had adapted to a "new reality" (Table 4, quote 3K). Handling the care of their child could also differ between the mother and father (Table 4, quote 3L).

Valuing NightWatch

NightWatch was valued differently, depending on parental anxiety and their own developed protective behavior. Pre-intervention interviews suggested that parents were interested in using NightWatch, and several felt that the NightWatch would show promising results (Table 5, quote 4A). For many parents, NightWatch provided an extra backup, so they could let go and get their sleep back (Table 5, quote 4B). In some cases, NightWatch immediately provided relief (Table 5, quote 4C). In contrast, others emphasized that NightWatch could add extra support but would not suddenly relieve their anxiety or relax the domestic scenario (Table 5, quote 4D). It appeared that the value of NightWatch was not only linked to its detection performance but more associated with parents' flexibility in their routine to adjust to a new device. One mother described that she could not exchange her old device for NightWatch, even though it had better performance for seizure detection as she was so used to the old, and changing would be too much of a hassle (Table 5, quote 4E). Parents often experienced such a high burden of care that there was no or only a little flexibility in adjusting their daily routine, including their protective behavior.

As a fluctuating course often characterizes epilepsy, parental needs for an SDD could also change over time (Table 5, quote 4F). Parents expressed their possible future need for NightWatch if seizure type would change (Table 5, quote 4G) or the seizure-related shout that always woke them up would disappear (Table 5, quote 4H). Some parents mentioned that it would be nice to use NightWatch only during changes in anti-seizure medication so that leasing options could be convenient (Table 5, quote 4I). The investment for continuous NightWatch usage, financially and personally (i.e., the burden of changing daily routine and possible false alarms) was too high for some parents (Table 5,

Table 5 Illustrative quotes for the theme: Valuing NightWatch

Quote	
4A	Case 3: Boy, 9 years, ID. Legal representative: <i>Well, I read different things about NightWatch, and they were all positive. So, I expect a positive result.</i>
4B	Case 10: Girl, 7 years, ID. Mother: <i>What NightWatch adds? For me, that piece of backup, that I'm not alone watching her. What if I do fall asleep, it is okay.</i>
4C	Case 17: Girl, 10 years, NID. Mother: <i>The device immediately gave me peace, although I didn't have the confirmation, yet that NightWatch would alert for her convulsions.</i>
4D	Case 13: Boy, 12 years, ID. Father: <i>For us it's an extra support. But that doesn't mean that we are suddenly relaxed and our sleep is improved. That is just not possible.</i>
4E	Case 16: Boy, 10 years, MID. Mother: <i>It's quite a nice device, but for us it didn't have any added value. We already have another device, and we are used to that, it is quite a hassle to change to a new system.</i>
3F	Case 8: Girl, 13 years, NID. Mother: <i>At the moment she doesn't have any seizures, so we don't need the NightWatch. Maybe in the future. Back in the days, I really needed this device.</i>
4G	Case 19: Girl, 5 years, ID. Father: <i>In the current situation NightWatch is not adding value. But she just changed her anti-seizure medication, so maybe the seizures will change too and then we are going to need the device badly.</i>
4H	Case 15: Boy, 11 years, MID. Mother: <i>No, we don't want to keep using NightWatch, because he always screams, so we respond faster to the sound from the baby monitor. [...] If his seizures would change, NightWatch would definitely be a good option.</i>
4I	Case 18: Girl, 16 years, ID. Mother: <i>Yes, I think renting the system could provide a nice solution for parents in times their child has to adjust to medication changes.</i>
4J	Case 11: Girl, 12 years, ID. Mother: <i>I also have all the regular house costs and I don't have a money tree in the backyard. It is quite an amount for a device, something I must consider at least three times: is it really worth it?</i>
4K	Case 15: Boy, 11 years, MID. Mother: <i>It would be helpful for us if NightWatch could be extended with a sensor for sound. Because it's way nicer to wake up by the sound of an alarm than the scream of your child.</i>
4L	Case 14: Girl, 6 years, NID. Mother: <i>The short power cord limits the range of the system, yes, that was the biggest problem. It would be nice to have a detection system which enables me to sit outside in the summer, while monitoring my child.</i>
4M	Case 7: Boy, 14 years, ID. Mother: <i>All those technical alarms, it would be better if they could be turned off, because they drove me crazy.</i>
4N	Case 9: Boy, 6 years, MID. Father: <i>Those heart rate graphs really give us a nice insight and overview of what's happening during the night. I immediately took a picture of it and sent it to his neurologist to show: look, it's not going well.</i>
4O	Case 19: Girl, 5 years, ID. Father: <i>I would say: rather 20 times too much than one seizure missed.</i>
4P	Case 8: Girl, 13 years, NID. Mother: <i>You trust the device will give an alarm during a seizure, so any false alarm is no problem for me.</i>
4Q	Case 12: Boy, 14 years, ID. Father: <i>Okay, if there was one false alarm per week, that would have been acceptable. [...] But there were too many if it starts beeping for nothing, for me that's worse than alerting too late or not at all.</i>

ID Intellectual Disability, MID Mild Intellectual Disability, NID No Intellectual Disability.

Some quotes are slightly modified to improve readability. Names are fictitious.

quote 4J). Especially in periods with low seizure frequency, this investment did not outweigh the low risk of missing a seizure; thus the course of epilepsy impacted parental needs.

Other parents emphasized the importance to adjust the device to their situation, e.g., by adding an audio sensor (Table 5, quote 4K), extend the range of the base station (Table 5, quote 4L), or turn off the sound of the “technical notifications” (Table 5, quote 4M). Providing insight and an overview of the night to share with the neurologist was stated by some parents as motivation to use NightWatch (Table 5, quote 4N).

There was significant variation in the acceptance of false alarms; most parents preferred false alarms over missed seizures (Table 5, quote 4O), but the number of false alarms outweighing missed seizure varied. This seemed to be mainly dependent on how parents handled care and experienced their care burden. Some parents were not concerned by false alarms, as long as the device would also alert them for a seizure (Table 5, quote 4P), while others stated that a high number of false alarms turned out to be worse than missing a seizure (Table 5, quote 4Q).

DISCUSSION

Driven by the fear of child loss, parents of children with epilepsy developed a personal protective behavior toward their child. This behavior could help parents to feel in control of their circumstances and decrease their fear. Conversely, monitoring every aspect of their child’s life could also increase the burden of care, with feelings of losing control, which leads to a vicious circle. Parents felt a great responsibility to protect their child and often had difficulties handing over the care due to their child’s specific needs. This responsibility further increased their burden of care, which may complicate the use of NightWatch. The extent to which NightWatch could support the family’s home circumstances depended mainly on the flexibility in the parents’ existing protective behavior. The way parents handled the care of their child and experienced the burden of care influenced their perceptions of the added value of NightWatch.

Symptoms of anxiety in parents of children with epilepsy were previously reported.^{3, 20} Still, our results complement these findings by illustrating what parents are afraid of and how this influences their behavior. We established that parental anxiety fluctuates over time alongside the changing seizure frequency, but it was not always related to changes in seizure frequency. Some parents

experienced a constant fear. A recent study assessing parents of children with epilepsy also suggested that parental anxiety and depression were not only correlated to epilepsy-related factors but also to parental resources (i.e., available tools to handle stressful situations) and the child's degree of behavioral difficulties.²¹

Our results show that parents felt a strong responsibility to protect their child, which was influenced by their child's behavior and specific needs. This protective behavior is also seen in other qualitative studies on parents of children with different chronic or life-limiting conditions.²²⁻²⁴ Parents described their caregiving role as the 'protector', encompassing holding all knowledge of the child's unique needs and the complete responsibility of caring for the child,²² and the 'guard' to watch over and protect their child.²³ Parents of children receiving palliative care at home explained how they decided to protect their child maximally and how this protective behavior increased their workload.²⁴ Taking control as the protector requires extra effort and relieves parental stress as care will be arranged the way they prefer it.²⁵ Our study has also shown how protective behavior can influence the parental burden of care in both directions and confirms that this burden could be divided into a physical (i.e., constant alertness, organizing the care) and a psychological component (i.e., worries about the future). The parenting and childhood chronicity (PACC) model, based on interviews with parents, describes several features of the work required to raise a child with a chronic health condition.²⁶ Many of these components were also recognized in our study, including "parenting plus" (i.e., compensating for the child's delayed skills), "working the systems" (i.e., working with the health, social service, and education systems for their child) and "keeping yourself going". The latter describes how parents often felt they had no choice but to keep on going, driven by their commitment to do everything they could to help their child.²⁶ This specific drive was also reflected in our interviews. Still, we observed significant variation in how parents handled their child care, from keeping absolute control to balancing the care for their child and themselves and adjusting to reality. These different strategies might reflect different coping styles of parents, which are related to variations in parental QoL.²⁷

In many families, NightWatch added value by providing a backup and relieving the burden of seizure monitoring. NightWatch could not, however, take away the fear of child loss. There is limited evidence available on the effect of SDDs on parental fear and their perceived burden of care. The majority of SDD

studies focus on detection performance and do not examine the impact of SDD use on the family. In a cross-sectional survey study on SDDs and health-related QoL, including people with epilepsy and caregivers, most users reported moderate or more significant anxiety reduction after using an SDD.²⁸ This study, however, did not take into account what other strategies caregivers had developed to handle their anxiety and how this influenced the effect of SDD usage. For the successful use of SDDs it is essential to understand parental needs and flexibility to adjust their routine to a new SDD, and which SDD features can improve their anxiety and QoL. A qualitative study on caregivers' preferences for SDDs, using the context mapping approach, revealed several critical elements for SDD implementation, including the importance of gaining trust in a device and the possibility of personally adjusting device settings for different users.²⁹ Our results confirm these differences in parental needs for an SDD and add that parental needs can also fluctuate over time. For SDD developers, these inter- and intrapersonal differences in requirements may be challenging when designing a generic device. Another long-term prospective study evaluated the effect of nocturnal monitoring on QoL and sleep of parents of children with newly diagnosed epilepsy with validated questionnaires.³⁰ Families decided whether or not to use a device at the start of the study, and the ones who choose to do so, were randomly assigned to a mattress movement sensor or an audio baby monitor. No significant differences were reported in anxiety levels between groups, while QoL and sleep improved in all parents after 5-7 months, irrespective of whether they used a device and which one.³⁰ This may implicate that newly diagnosed epilepsy has a negative impact on parental QoL and sleep, which gradually stabilizes over time. In our cohort of children with refractory epilepsy, we found that epilepsy still significantly impacted parental QoL and sleep, even years after the diagnosis. Over time, stabilization was influenced mainly by how parents experienced and handled the burden of care and if an SDD could support their circumstances.

Limitations

We included parents of children with refractory epilepsy treated in tertiary centers, participating in the PROMISE study. This may have led to selection bias as most children had severe epilepsy. Additionally, only children with nocturnal major motor seizures were included because NightWatch is designed to detect those seizures only, so the results might not be generalizable to parents of children with other, or less severe, seizure types (e.g., only absences). The informed consent for an interview was given before the intervention period and

was therefore not influenced by the device's detection performance and parent experiences. Most parents agreed to participate in an interview. The sample mainly consisted of native Dutch-speaking parents from all over the country. We aimed to include a balanced number of mothers and fathers, but most responders were mothers, probably because they were the child's primary caregiver. One of the authors who analyzed the data (AvW) was also coordinating the PROMISE trial, which might have induced an interpretation bias.

The COVID-19 pandemic impacted the Netherlands around the beginning of 2020 and caused significant changes in the family's context and interview settings. The burden of care was significantly increased, as children were bound to their homes due to the lockdown, and their familiar daily structure and outsourcing of care was mostly lost. These changes may have impacted the way parents valued NightWatch. Additionally, we were forced to conduct part of the interviews online instead of in the home environment, which could have influenced the parents' responses. Yet, the majority of interviews (14/21) were conducted in the home environment and outside the COVID-19 pandemic.

Implications for practice

We learned that the need for an SDD could fluctuate over time, depending on changes in seizure type or frequency. Additionally, we observed the need to make personalized changes to the device (i.e., changing alarm thresholds). We recommend SDD developers and companies to offer leasing options and the possibility to personalize the device settings, provided that usability and support is warranted. Every person with epilepsy is different and so are their parents. It is an unrealistic expectation to find a device that will fit all, and developers cannot take every specific need into account. It is essential to appreciate these differences and keep an open mind for adjustments to improve implementability.

All parents from our study developed specific strategies to protect their child, which influenced the extent to which NightWatch was beneficial. We recommend that healthcare professionals take full account of the burden of care and the personal protective behavior when discussing SDD implementation.

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CHAPTER 8

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