Wearables in real life: A qualitative study of experiences of people with epilepsy who use home seizure monitoring devices

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OBJECTIVE: To explore the experiences of people with epilepsy using wearables for home seizure monitoring.

METHODS: Nine people with epilepsy participated in eighteen semistructured individual interviews before and after home monitoring with wearable seizure monitoring equipment. An open-ended interview guide was used to encourage the participants to elaborate on their thoughts and experiences. Interviews were analyzed using a three-level process inspired by the philosopher Max van Manen.

RESULTS: The overall findings illustrate that patients experienced being placed in the spotlight when wearing wearables. The meaning of being in this spotlight is reflected in three themes: Becoming vulnerable through exposure, Standing alone while being with others, and Having a renewed life situation. The analysis and interpretation showed that although the participants expressed readiness to use the wearables, they were less willing to do so after a few days of monitoring. The visibility of the devices influenced how they experienced themselves and were perceived by others.

CONCLUSION: For people with epilepsy, wearables are more than just technical tools; they have a significant existential impact on everyday life. Wearables spotlight the epilepsy condition, and this causes people with epilepsy to experience an existential disruption, as they experience being exposed and vulnerable. This results in a renewed way of perceiving oneself. Nevertheless, wearables also validate epilepsy symptoms, thereby reducing the uncertainty related to epilepsy.

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1. Introduction

In the past decade, numerous wearable health devices that can be used to monitor sleep, physical activity, and health have emerged [1,2], and this technology is increasingly utilized in the healthcare sector [1,3]. Wearable health devices to monitor epilepsy (hereinafter wearables) are intended to function as a solution for objective seizure quantification and alarming [4]. Subjective seizure counting has long been regarded as unreliable [5], but it is still clinically relied upon due to the lack of a good objective alternative [6]. Despite medical treatment, up to 30% of people with epilepsy (PWE) are not seizure free [7]. The unpredictable nature of seizures can cause distress and lead to social isolation [8]. Wearables that provide reliable seizure monitoring can individualize and improve health and self-care, allowing for more personalized health care [2].

When monitored in an epilepsy monitoring unit (EMU), PWE are exposed to specialized medical equipment, such as video monitoring, that can compromise personal freedom and privacy [9]. EMU monitoring serves an important diagnostic role, but it is infeasible and excessive for long-term outpatient seizure monitoring. New methods of seizure detection are being developed for this patient group, and in recent years, an increasing number of wearable devices and digital technologies have become available [10]. Studies have shown that 80–94% of PWE are willing to explore the use of wearables [10,11]. The visual appearance, comfort, and accessibility of such devices greatly affect how willing PWE are to use wearables outside the hospital. Nonetheless, the fear of social exclusion and stigma can hinder the use of wearables [12].
Previous research on the readiness for wearables among PWE [13] has shown that wearables are valuable because they enable a better understanding of the life situation of PWE. The technology is thus more than merely a technical tool: it can be considered an esthetic and existential artifact that acts as a lifeline between PWE and their healthcare providers. Wearables legitimize the signs and symptoms of epilepsy, perhaps leading to improved acknowledgment from health professionals, friends, and relatives. Indeed, wearables have been identified as a tool that could potentially improve the quality of life among PWE [13].

Studies have investigated the potential barriers and facilitators related to the use of wearables among PWE. Most research has focused on the technical and visual aspects of devices, and little is known about the potential impact of wearables on the everyday lives of PWE. There is sparse knowledge of the experiences of PWE in regard to wearables, especially during home monitoring (i.e., “in-the-wild” monitoring). In the wild indicates the use of wearables in an everyday setting, such as during work, shopping, and sleep. The aim of this study was to explore the experiences of PWE regarding in-the-wild use of wearables.

2. Method

2.1. Design

A qualitative phenomenological approach inspired by the philosopher Max van Manen was used [14]. With this approach, it is possible to gain new knowledge of how it is to be a person using wearables in the wild. The methodology combines a descriptive presentation of lived experiences with an interpretive understanding and is used in this work to explore what is significant to PWEs. A lived experience description is a vivid textual account of an experience just as it was lived through [14]. It describes a particular instance of an experience in concrete terms, avoiding abstraction, introductions, rationalizations, causal explanations, generalizations, and interpretations [14]. Thus, the goal of this study was to disclose what was experienced and how it was experienced as a means of examining and better understanding new meanings and appreciations related to the use of wearables.

2.2. Participants and settings

Participants were invited to participate in the study when admitted to the EMU or when visiting the outpatient epilepsy clinic at a regional university hospital in Denmark. These participants were approached by one member of the clinical team at the department and subsequently by the researcher JMN. Ten participants were invited to participate; one declined the invitation due to personal reasons. Five women and four men were included in the study (Table 1). Participants ranged in age from 28 to 44 years. Eight participants had had epilepsy for more than six years, and one participant was diagnosed within nine months prior to inclusion in the study. The authors recruited through a purposeful sampling process [15] and strove to recruit participants of both genders and of varied ages and disease durations. This participant diversity provided varied contexts within which to investigate the phenomenon of using wearables in the wild. The participants were required to speak and understand Danish fluently. Furthermore, participants who were not considered able to manage the wearables (e.g., due to cognitive decline, psychiatric comorbidities or abuse problems) were excluded from the study. All participants were informed verbally and in writing about the purpose of the study and gave informed consent.

In the-wild monitoring was offered only for research purposes. However, most participants were very interested in participating because they hoped that this monitoring would improve their own and their healthcare professionals’ knowledge of epilepsy.

2.3. Wearables

Three wearable devices were used to monitor each participant. The devices included a portable electroencephalography amplifier with two channels, an electrocardiography device fixed to the participant’s sternum with a patch electrode, and one to four accelerometers attached to the limbs using small patches. Each participant was instructed by LSO and JMN on how to manage the wearables and was thoroughly prepared for possible technical challenges associated with using the devices. This process took approximately an hour. Participants were encouraged to wear the devices day and night for up to five consecutive days. However, they could freely choose when they wanted to wear the equipment, as it could easily be removed and later reattached. Furthermore, the participants were encouraged to keep seizure diaries and to take notes regarding technical difficulties, adverse events, and notable experiences associated with using the equipment. While being monitored, the participants were encouraged to follow their regular routines, including going to work and socializing; this was possible due to the wearable nature of the devices and the lack of video monitoring. The participants were given the number of a direct telephone hotline to the investigators to ensure that they felt safe and confident when managing the wearables. One participant who experienced only nocturnal seizures chose to use the wearables only in the evening and at night. No technical problems or adverse events were reported during in-the-wild monitoring.

2.4. Data collection

In this study, data were collected through interviews conducted in the homes of the PWEs. In these interviews, the researchers

| Participant | Age (yrs) | Sex | Marital status | Employment  | Epilepsy duration | Seizure type | Seizure frequency | Monitoring time (days) |
|-------------|-----------|-----|----------------|-------------|-------------------|--------------|-------------------|------------------------|
| P1          | 44        | F   | Living with partner | Employed    | 24 years          | FIAS         | 1/month           | 3                      |
| P2          | 34        | F   | Living with partner | Unemployed  | 9 months          | Unknown      | Daily             | 4                      |
| P3          | 42        | F   | Living with partner | Employed    | 7 years           | FTBTCS       | 1–2/week          | 3                      |
| P4          | 22        | M   | Living alone       | Unemployed  | 6 years           | FTBTCS       | 1/month           | 4*                     |
| P5          | 42        | F   | Living with partner | Employed    | 7 years           | FIAS         | 1/week            | 4                      |
| P6          | 29        | M   | Living alone       | Unemployed  | 11 years          | FTBTCS       | Daily             | 3                      |
| P7          | 44        | F   | Living with partner | Unemployed  | 24 years          | FIAS         | 1/year             | 4                    |
| P8          | 30        | M   | Living alone       | Employed    | < 20 years        | FIAS         | 2/month           | 3                      |
| P9          | 28        | M   | Living alone       | Student     | 10 years          | NFFL         | Daily             | 4                      |

FIAS: Focal impaired awareness seizures.
FTBTCS: Focal temporal lobe epilepsy with secondary generalizations.
NFFL: Nocturnal focal frontal lobe epilepsy.
focused on discovering patterns of meanings and variations that described the essential meaning of what it is like to be a person using wearables in the wild [14]. Hermeneutic phenomenology is the study of the lifeworld or of the world as experienced by an individual. This can be explored through the five lifeworld existentials: lived body, lived self-other, lived space, lived time, and lived things and technology [14]. These existentials are fundamental, common themes that lie within all human lives regardless of the individuals’ histories, social situations, and cultures. According to van Manen, existentials are helpful as a guide for reflections through the research process [16]. Thus, the five lifeworld existentials were used to structure the interviews, with the purpose of exploring all aspects of the participants’ experiences of the phenomenon of using wearables. Although existentials will always overlap with each other, in a given situation one existential might be more pervasive than another [16]. In this study, the existentials of the lived body and lived self-other naturally came more into focus, resulting in more questions being directed to these existentials. The questions in the interview guide were not developed with reference to the known epilepsy literature, as the intention was to maintain an open attitude throughout the data collection.

In practice, data were collected by inviting PWE to participate in two interviews. The interviews were conducted in the participants’ homes to provide a visual context for the use of wearables in the wild and used a semistructured interview guide (Table 2) inspired by Kvale [17]. With the hermeneutic phenomenological approach, the interviewer strived to create an open atmosphere by listening and paying attention to what was said. The interview guide was used to maintain a focus on the phenomenon while also responding to the participant’s described experiences and thoughts.

A total of eighteen interviews were conducted. The initial interview was conducted before monitoring began to gain insight into any immediate thoughts the participant might have on using the wearable in the wild. After monitoring, a comprehensive interview was conducted to elaborate on experiences the participant had after wearing the devices in the wild. Interviews were conducted until data saturation occurred [18].

All interviews were conducted by LSO as individual face-to-face conversations. The interviewer had no clinical experience with epilepsy, a fact that provided independence and an open attitude during the interviews and subsequent interpretation [19]. The participants were encouraged to provide responses regarding their experiences and expectations that were as thorough and descriptive as possible and were also encouraged to share examples from their everyday lives related to the wearables.

Data were collected between July 2020 and October 2020. As the data were collected during the COVID-19 pandemic, the researchers were attentive to how this might affect the participants’ opportunities to perform daily activities and to be physically present at their workplaces. However, during this period, pastime activities and workplaces were not affected by a lockdown in Denmark. All interviews were audio-recorded and transcribed verbatim, yielding 101 pages of text. The excerpts used in this article were translated into English by LSO, with JMN and MB confirming translation accuracy or suggesting improvements until consensus was reached.

2.5. Ethical considerations

The ethical guidelines set forth in the Helsinki Declaration and the guidelines offered by the Nordic Nurses’ Federation were followed during the study and data collection. The study was approved by the Regional Committee on Health Research Ethics (SJ-725) and by the regional data protection agency (REG-121-2018). When interviewing participants, the interviewer must be aware of the asymmetric relationship between the interviewer and the participant [17]. Humbleness and attentiveness were strived for during the interviews to avoid causing the participants any harm when they were interviewed about personal themes [20].

2.6. Data analysis

To gain insight into the experience of using wearables in the wild, the interviews were interpreted by performing a thematic analysis that was inspired by the analytic steps (Fig. 1) described by van Manen [14]. This method included dynamic switching between wholistic, selective, and detailed phases, opening up insight into the existential phenomenon [14]. In practice, this meant that the interviews were first read repeatedly and reflected upon in their entirety (wholistic phase). The overall research question “how do people with epilepsy experience using wearables during in-the-wild monitoring?” guided the search for wholistic descriptions and more general descriptions of the phenomenon. This made it possible to get a sense of “what was going on” and “what has been said” during the interviews. Second, in the selective phase, quotes were identified that had special significance with respect to how the participants experienced wearing the wearables. To identify quotes that were endowed with significant meaning, we created themes that enabled us to capture meaning and to better reflect on what was said during the interviews. This phase was characterized as a process in which the choice and selection of themes were discussed thoroughly and continuously within the research group to validate the quality and trustworthiness of the themes. Finally, in the detailed phase, individual sentences and paragraphs were examined with the purpose of choosing representative and illustrative quotes that exemplified the meaning and interpretation within the theme and subthemes in the analysis [14]. In practice, this phase leads to better insight into PWE’s experiences of using wearables in the wild. Author LSO performed the initial analysis, and all authors then discussed the presented themes and findings as a basis for validating their meaning and interpretation.

3. Results

3.1. The essence: being placed in the spotlight

The essential meaning of using wearables in the wild to people living their everyday lives with epilepsy is characterized by the
experience of being placed in the spotlight. The participants experienced wearables as a constant reminder of their epilepsy that visually confronted both themselves and people around them with the fact that their lives were attuned by the condition. The participants shared that this experience made them feel affected by their condition in an existential way; hence, wearables encouraged new insights into their being-in-the-world. At the same time, wearables provided a long-awaited experience of an attempt to validate their epilepsy symptoms. This reduced uncertainty caused by the epilepsy provides comfort and hope for clarification of their experienced symptoms. Furthermore, the analysis showed that although the participants initially expressed readiness to use the wearables, they were less willing to do so after a few days of monitoring. The visibility of the devices influenced how they experienced themselves and how they were perceived by others.

The essential meaning is further elaborated in three themes: 3.1.1 Becoming vulnerable through exposure; 3.1.2 Standing alone while being with others; 3.1.3. Having a renewed life situation.

3.1.1. Becoming vulnerable through exposure

Participants shared their feeling that wearables served as a reminder that something was different about them. Furthermore, they disclosed that wearing the devices made their condition and symptoms more readily visible, both when they were alone and when they were with others. This visual aspect of the wearables, which included the portable electroencephalography amplifier with visible electrodes, electrocardiography, and accelerometers, brought them into the spotlight, and this made them feel uncomfortable and vulnerable. The participants indicated that they found this unpleasant because being in this type of spotlight was experienced as exposing epilepsy. Furthermore, it influenced how they dealt with the disease. For the participants, every single piece of the wearables represented a bodily exposure of them as vulnerable patients with epilepsy. Because the devices shed light on their condition, they considered themselves more fragile than others, and wearing the devices reminded them of how affected they had been and of the inescapable nature of their medical condition. Some had learned to live ordinary everyday lives in which they were rarely confronted with epilepsy. However, the visibility of the wearables focused their attention on the experience of their condition, including its potentially life-threatening nature. This confrontation resulted in uncertainty and thoughts about future aspects of living with epilepsy. The participants revealed that the wearables prompted peripheral and unknown relations to ask questions about their epilepsy to which they had to respond. The way participants felt about having to discuss their epilepsy with others was related to how they identified themselves as persons. One participant said:

“(….) It is nice that we take care of each other. But if you are not the type of person who wants to stand out from the crowd, and are in a position where you do not know exactly what you should reply to questions, then it can be a bit uncomfortable, because I don’t like answering and I don’t like calling attention to myself.” [P2]

The visibility of the wearables prevented participants from hiding their epilepsy from their friends and families. This created a vulnerability about their life situations that was influenced by the people around them. The participants felt that the increased attention was an invitation to openness related to their epilepsy. Most experienced a negative attitude toward this attention. According to the participants, in an ordinary life with epilepsy, they were able to decide for themselves whom they wished to tell about their condition, except in situations in which they had seizures in public. However, using wearables required them to tell other people about it. This unwanted focus made the participants uncertain about how other people viewed them and caused them to fear that others would consider them vulnerable; being unable to decide for themselves with whom they would share their condition resulted in the experience of wearables being perceived as uncontrollable elements. This could trigger uncertainty, as the participants did not know when they would be confronted with questions about their epilepsy. In that sense, the participants revealed that they spent much energy trying to hide the wearables. One participant said:

“(…) yesterday, I spent time with my study group and I had to take the bus. I did not think it was fun to wear it in that situation, so I had a big sweater on, trying to prevent people from looking too much at me (…))” [P1]

Hiding wearables allowed participants to avoid unwanted attention from other people. This also served to reduce the constant reminder that their lives were affected by epilepsy. According
to the participants, they were attentive to moments and situations in which they wished to hide the wearables. During the analysis, it became clear that using wearables in public served to make the invisible disease visible. The visibility caused uncertainty for the patients, and attempts to hide the wearables might fail. This meant that the participants experienced a lack of control over who would know about their condition. Participants shared that this had a major impact on how they related to their epilepsy. Thus, it was important for the participants to be in control of when they wanted to inform others about their condition. A participant described this by saying:

“(…) nobody at my workplace knows that I have epilepsy, so if I had to wear this at work, I would have to explain a lot and personally it would push my limits. Everybody knew about it at my former workplace, so in that situation it would not have been that big a deal.” [P5]

According to the participants, the wearables signified increased severity of their epilepsy to their family and friends. Epilepsy was not something that was spoken about in daily conversations within the family prior to utilizing the wearables. Therefore, family and friends did not always identify the participants as persons living with epilepsy. When they saw the participant using the wearables, it appeared as though the epilepsy had suddenly worsened. This could be frightening, especially for children. Being looked at differently caused the participants to experience a need to protect their loved ones, as they were aware that they were now perceived as more fragile. One participant described how her children reacted during the monitoring:

“. . . I could sense that they thought it was, I don’t know if they were worried, but it was definitely like it became very obvious to them.” [P2]

Another participant recounted the reaction she had from her daughter:

“When she realized that I had these things on, she became very scared and became convinced that now it was all very serious.” [P5]

In this direct way, the relatives were impacted by transforming the participants’ readiness to use wearables into an unwillingness.

3.1.2. Standing alone while being with others

The presence of children had a negative influence on the participants’ perceptions of the acceptance of wearables. This affected their willingness to wear them in a way that allowed others to see them. One participant was asked to describe how using wearables among family and friends affected her everyday life:

“It (the epilepsy) is nothing we normally talk about; they assume that everything is fine. So when I suddenly wear these devices, they probably worry that now there is something wrong, and that will require a lot of explaining.” [P5]

The close families and friends of the participants were attentive to the visibility of the epilepsy. One participant was told by her husband to “cover up” [P7] before leaving the house because he worried about the unwanted attention the wearables could draw. Adolescent relatives of the participants felt “embarrassed” [P2] if they were seen in public with a participant using the wearables. This negatively influenced the participants’ willingness to use them. When relatives expressed these concerns, the participants became worried that the wearables would create a distinction in how other people perceived them. This caused them to experience being left out of the community and left them in a lonely position. The visual appearance of the wearables was important: the participants shared their feeling that if the devices had been modern and small, they would not have caused the wearer to stand out from the crowd. The participants indicated that the less visible the wearables were to them and to those in their surroundings, the more willing they were to wear them. This surprised many participants because during the preliminary interviews most of the participants described themselves as indifferent to what other people thought of the wearables. They discovered that, in reality, the visual aspect had a significant impact on how they experienced everyday life and on how they were perceived by others. One participant described this, saying:

“I realized that how people think of me actually means more to me than I thought. Normally, I think that people can look all they want, but . . . when it came to it, I didn’t think it was that pleasant.” [P1]

The participants offered many suggestions about how the devices could be made more attractive. One participant said:

“(…) there exists all these modern purses like those I have over there (points at her handbags and purses in the room). If you could provide some of those (…), then it looks more modern. Perhaps the men would not want to wear them, but as a lady, then you could wear it around the belly, if that is what you want, and that would be a lot fancier.” [P7]

The participants also suggested that the wearables could be made to look like smartphones or that the electrodes could be wireless. The wearables needed to reflect recognizability to maintain consistency with everyday life without drawing increased attention to themselves. The participants clearly preferred not to stand out. An example was one participant who said:

“(…) If you could make it to the size of a smartphone and you could just put it in your belt, then it wouldn’t be that big of a deal, so it would be like] walking around with a fanny pack.” [P6]

3.1.3. Having a renewed life situation

Through in-the-wild monitoring, participants began to think differently about how they experienced themselves and their epilepsy. This meant that existential thoughts of how they perceived their identity in relation to being a human whose life was affected by epilepsy emerged. Although the participants had previously stated that they would be willing to wear wearables in public, they came to a new recognition of how the devices, in reality, affected their lives. This new recognition meant that the participants began to perceive wearables not simply as technical devices but as components that were rooted deeply in their existential way of being-in-the-world. Through the use of wearables, they experienced increased personal attention to their epilepsy. For participants who only rarely experienced seizures, the wearables became a clear reminder of something they usually could forget. An example of this was when a participant said:

“Well, it reminds me that the disease is present, and the seizures are possible. When I am wearing a fanny pack with all these wires, I can’t really ignore it the same way as I can [normally] forget it when I’m cooking or spending time with the children through an ordinary day.” [P1]

Our analysis revealed that wearables mobilized a variety of existential thoughts about living with a disease, many of which impacted everyday life. Using wearables caused the participants to feel that the disease was more in the forefront of their lives than it had been previously. This meant that they considered other aspects of living with a disease more than they did before using wearables in the wild. An example of this was a participant who said:

“(...) It (the epilepsy) is nothing we normally talk about; they assume that everything is fine. So when I suddenly wear these devices, they probably worry that now there is something wrong, and that will require a lot of explaining.” [P5]
“(...) people walk around with oxygen devices and all sorts of equipment, I think it has something to do with how you identify yourself with the disease. You become a little sick when you wear something like this.” [P2]

For those who were newly diagnosed or had numerous seizures, wearables were seen as a valuable tool that provided them with insight into their epilepsy. Some participants had been struggling for many years to understand and legitimize their bodily signs and experiences of seizures as they relate to themselves, their surroundings, and their healthcare providers. In this situation, wearables were perceived as an acknowledgment of their experience of having epilepsy. Wearing the devices helped them reduce their uncertainty about their symptoms and condition. One participant described it this way:

“(…) to have this equipment on, that is very serious, I feel that I’m being taken seriously (…) it seems more purposeful on the part of the department [Department of Neurology], when one is examined in that way.” [P2]

Most of the participants experienced regaining control regarding their epilepsy symptoms when using wearables. They all had hopes that wearables could provide insight into seizure frequency, seizure patterns, and the localization of their epilepsy, all of which could potentially assist health care providers in improving their medical treatment. An example of this was a participant who said: “(...) if it can detect it (the seizures), and they can say that I need another treatment, that would be great.” [P1]

While experiencing helpfulness about a potential clarification of their symptoms, the participants also felt stressed during monitoring. Most participants had previous experience with inpatient monitoring in the EMU. In-the-wild monitoring allowed the participants to maintain everyday life with family and friends, regular activities, and work. However, even though the wearables provided an opportunity for the participants to stay in their home environment, they still experienced stress regarding monitoring the seizures. On the one hand, they were interested in recording a seizure. On the other hand, a seizure was normally something they tried to prevent. One participant said:

“I have thought a lot about it, and it is like when you work in emergency preparedness (…), it is good for the community if nothing happens, but it is really boring to be at work. And it is the same with this because I had hoped that it could not register anything. After all, I have not had a seizure while monitoring, but at the same time, I would have wanted there to be something, because it could help me localize something (…)” [P1]

The participants shared that they were equally stressed about having a seizure when in the EMU and during in-the-wild monitoring, but said that at home they were better able to relax and feel comfortable. This ambiguous situation increased attention to appearing” when illness changes one’s abilities. The consciousness becomes directed toward the parts or functions of the body that do not respond as one wants them to. Hence, these parts become more visible than they previously were [21]. Our study shows how wearables can be seen as technical artifacts that render the body dys-appearing to the people who wear them, meaning that PWE become more attentive to their bodies as abnormal and different when wearables are used. Under these circumstances, the PWE experienced their existence in a new way, caused a renewed and more visible relation to epilepsy. This implies that wearables might impact the way PWE perceive themselves and how others view them. In light of being confronted with this new way of perceiving themselves and their epilepsy, wearables make their bodies reappear. This new insight provides valuable knowledge to health professionals who work in epilepsy monitoring when considering the practice of health pedagogy. Based on our findings, we argue that it is important that health professionals also consider the existential impacts similar technical devices can have on people who are being monitored.

Our study illustrates that for PWE wearables can be a tool that allow them to experience acknowledgment of their symptoms. Thus, wearables have the potential to provide an experience of legitimization in relation to everyday life with epilepsy. This is consistent with previous research [13]. Our study further elaborates on how the use of wearables can help PWE deal with uncertainty related to epilepsy symptoms. Uncertainty, here, can be defined as the inability to determine the meaning of illness-related events, a cognitive state that occurs when individuals cannot adequately categorize or structure an illness event due to insufficient cues [22]. Uncertainty in illness often occurs in situations that are unpredictable, complex, or ambiguous. Inconsistent information or lack of information also creates uncertainty. Our study reveals that living with epilepsy can mitigate and exacerbate a sense of uncertainty [22]. There is a complex relationship between the use of wearables and the experience of uncertainty in epilepsy that depends on the context and the person. The uncertainty can be decreased by the use of wearables because they provide PWE with hopeful expectations, as the improved categorization of symptoms as epileptic or nonepileptic that the wearables provide can pave the way for a better understanding of such signs.

Our study provides valuable knowledge regarding the importance of the visual aspect of wearables to PWE, especially as it is
intertwined with perceptions of uncertainty experienced by friends and relatives. Our study showed that PWE experience the visual aspect of wearables as impacting their presence within the context of family and friends. PWE experience that their relatives perceive wearables as a confronting element of epilepsy, leading to uncertainty and worry. These experiences affect the willingness of PWE to use wearables, and it came as a surprise to them that they were affected in this way. We argue that this new insight should be recognized by healthcare professionals in clinical practice so that they may prepare future PWE to expect more attention to their epilepsy than they might anticipate prior to in-the-wild monitoring. Furthermore, comfort and support should be offered by healthcare professionals during monitoring to mitigate the potential existential struggles that PWE using wearables may experience. Mishel and Clayton point out that when relatives experience uncertainty, it can impair their ability to provide support for a person [22]. Therefore, providing information and encouraging the involvement of relatives when using wearables is essential for increasing the willingness of PWE to use future health technology.

5. Strengths and limitations

The current study provides valuable insights into the perspectives of PWE who use wearables for in-the-wild seizure detection. The participants were interviewed before and after monitoring, allowing the study to analyze both their expectations and their experiences. The participants were monitored for up to five consecutive days while they used a specific technological setup. This is a limitation, as the results may not be generalizable to longer periods of monitoring or to experiences involving the use of different equipment. The participants were free to choose when they wanted to use the wearables during the day. This allowed the study to explore the situations and circumstances under which they were willing to use the devices.

In this study, we interviewed nine participants. The sample size is not extremely relevant in qualitative research since the number of participants does not reflect the quality of the study. Qualitative research requires in-depth analysis and interpretation. Interviews were conducted until data saturation occurred and new insights were no longer being obtained [23]. Because the method used in this study involved interpretation of the findings, it is important to note that other researchers might have other findings and conclusions. However, in this study, all authors discussed the themes and findings throughout the analysis process. This extensive collaboration reduced the possibility of personal interpretations and biased decisions related to the data material [19]. Through the use of a qualitative approach, it was possible to gain deep insight into user perspectives [23], and this provided important insights into, e.g., designing new wearables.

5.1. Implications for practice

Knowing that wearables are associated with relational considerations and that they impact the users’ existential experiences, there are pedagogical considerations that are relevant to future studies of PWE using wearables. Healthcare providers should acknowledge the existential impact wearables have on PWE and should verbalize these potential struggles when introducing in-the-wild monitoring.

6. Conclusion

This study contributes novel knowledge of how PWE experience using wearables for in-the-wild monitoring as it brings attention to how it is to experience being placed in the spotlight. For PWE, this is an existential disturbance of their way of being in the world. In this sense, this study validates the notion of wearables as more than simply technical devices; they also have a significant existential impact. Nevertheless, wearables validate essential aspects of the users’ epilepsy, making it easier to accept and understand symptoms related to their diagnosis and reducing uncertainty.

Competing interests

The authors declare no conflicts of interest.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Author contributions

JMN and LSO were equal contributors as first authors of this publication. JMN recruited the participants. LSO collected data. CS worked as extern facilitator and academic resource. JMN, TWK, CS, MB and LSO all contributed to the manuscript preparation.

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