RESEARCH ARTICLE

# Preferences and User Experiences of Wearable Devices in Epilepsy

## A Systematic Review and Mixed-Methods Synthesis

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## Abstract

### Background and Objectives

To examine the preferences and user experiences of people with epilepsy and caregivers regarding automated wearable seizure detection devices.

### Methods

We performed a mixed-methods systematic review. We searched electronic databases for original peer-reviewed publications between January 1, 2000, and May 26, 2021. Key search terms included "epilepsy," "seizure," "wearable," and "non-invasive." We performed a descriptive and qualitative thematic analysis of the studies included according to the technology acceptance model. Full texts of the discussion sections were further analyzed to identify word frequency and word mapping.

### Results

Twenty-two observational studies were identified. Collectively, they comprised responses from 3,299 participants including patients with epilepsy, caregivers, and healthcare workers. Sixteen studies examined user preferences, 5 examined user experiences, and 1 examined both experiences and preferences. Important preferences for wearables included improving care, cost, accuracy, and design. Patients desired real-time detection with a latency of ≤15 minutes from seizure occurrence, along with high sensitivity (≥90%) and low false alarm rates. Device-related costs were a major factor for device acceptance, where device costs of <$300 USD and a monthly subscription fee of <$20 USD were preferred. Despite being a major driver of wearable-based technologies, sudden unexpected death in epilepsy was rarely discussed. Among studies evaluating user experiences, there was a greater acceptance toward wristwatches. Thematic coding analysis showed that attitudes toward device use and perceived usefulness were reported consistently. Word mapping identified "specificity," "cost," and "battery" as key single terms and "battery life," "insurance coverage," "prediction/detection quality," and the effect of devices on "daily life" as key bigrams.

### Discussion

User acceptance of wearable technology for seizure detection was strongly influenced by accuracy, design, comfort, and cost. Our findings emphasize the need for standardized and validated tools to comprehensively examine preferences and user experiences of wearable devices in this population using the themes identified in this study. Greater efforts to incorporate perspectives and user experiences in developing wearables for seizure detection, particularly in community-based settings, are needed.

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## Glossary

**SUDEP** = sudden unexpected death in epilepsy; **TAM** = technology acceptance model; **TF-IDF** = term frequency-inverse document.

### Trial Registration Information

PROSPERO Registration CRD42020193565.

Management of epilepsy and clinical evaluation of novel therapies relies on accurate reporting of seizures. Currently, this is ascertained through subjective reporting from patients and/or caregivers. Subjective reporting is often inaccurate because patients have limited awareness or recollection of their seizures.[1,2] Objective methods for seizure detection such as wearable devices and integration of mobile health platforms hold promise for high-quality and real-time seizure monitoring, which may improve out-of-hospital, community-based care.

Many patients with epilepsy are reliant on family members or caregivers for assistance in managing their condition, which in turn affect their autonomy and privacy.[3] People with epilepsy, particularly those who have poor control of their seizures, are more likely to come from a low socioeconomic background and face difficulties with driving and employment.[4] In addition, there are often substantial stigma, anxiety, and depression associated with epilepsy. Therefore, it is essential to include the views, experiences, and desires of patients with epilepsy, their caregivers, and treating clinicians in the development and implementation of seizure monitoring technologies.

However, previous reviews of patient needs and preferences for wearable devices for epilepsy have not applied a systematic methodology[5] or examined broad neurologic disorders.[6] Therefore, this systematic review aimed to synthesize the needs, preferences, and experiences of people with epilepsy, caregivers, and healthcare providers using a prepublished systematic protocol and undertaking both descriptive analysis and thematic coding of the included studies.

## Methods

### Standard Protocol Approvals, Registrations, and Patient Consents

The protocol for this review was developed and prospectively registered on the PROSPERO (International Prospective Register of Systematic Reviews; CRD42020193565, July 22, 2020) in accordance with PRISMA guidelines.[7]

### Identification of Studies

Electronic database searches were conducted through PubMed, Web of Science, Scopus, and Cochrane Library (January 1, 2000, to May 26, 2021). Searches were conducted in the English language without study design or setting restrictions to identify studies reporting perspectives of patients with epilepsy, caregivers of patients with epilepsy, or clinicians involved in epilepsy care on user preferences, needs, and desires or experiences of patients with epilepsy in using noninvasive and ambulatory devices intended for seizure monitoring. We excluded studies that evaluated invasive or nonambulatory devices.

### Selection of Studies

Two reviewers (S.S., A.Y., or A.B.) independently screened titles and abstracts and reviewed full texts using Covidence (Veritas Health Innovation, Melbourne, Victoria, Australia); disagreements for inclusion were resolved with an independent reviewer (P.K.).

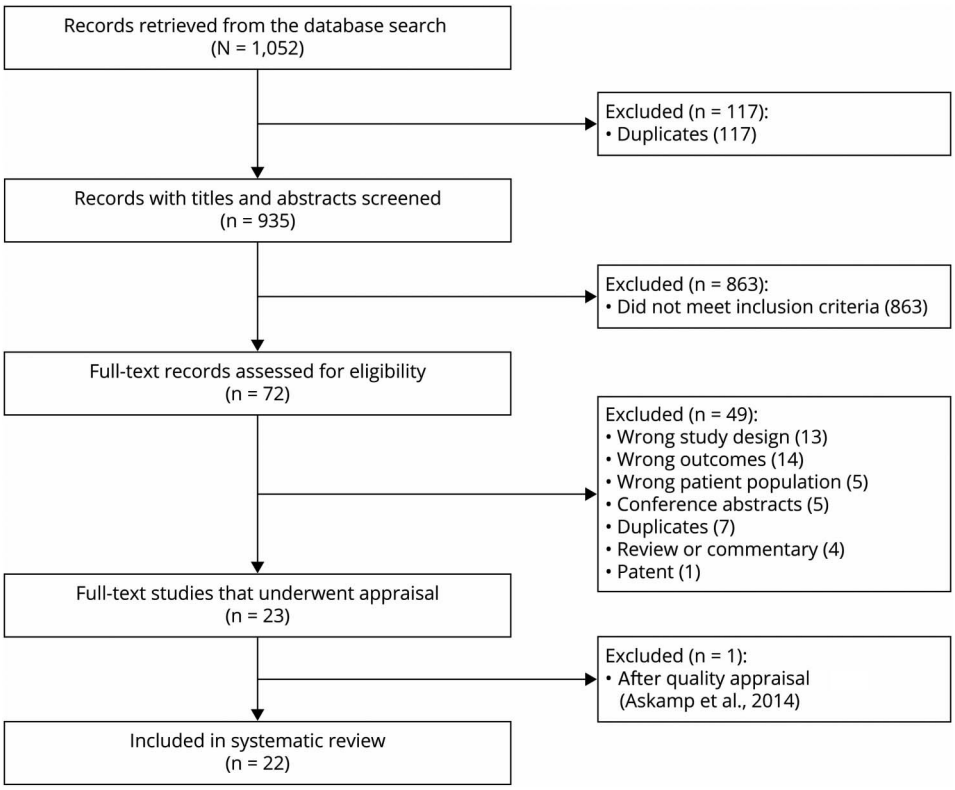
### Study Quality and Risk of Bias Assessment

Two reviewers (S.V., L.P., or N.A.L.) conducted a quality review of all included articles using the Joanna Briggs Institute critical appraisal checklist for cross-sectional or cohort studies and the Critical Appraisal Skills Program for qualitative studies. Disagreements were resolved with a third reviewer (N.A.L. or L.P.). Studies with a quality score below 25% on their quality assessment tool were excluded. A low threshold was used for inclusion in this systematic review because we aimed to examine the concept of wearable devices more broadly, without limiting our results to few-to-no high-quality studies.

### Data Extraction

A pretested data extraction framework in Microsoft Excel was used to extract and chart data from the included studies. One reviewer (S.S.) extracted data, including study identifiers (title, first author, year of publication, and journal), study design and setting, country, method of administration (e.g., in-person/face-to-face, and telephone), population characteristics, aims, quantitative outcomes, source of funding and reported conflicts of interests, ethics approval, study limitations, and any other reported findings. Demographic and clinical data including age, sex, ethnicity, types of seizures, time since diagnosis, symptom severity, number of antiseizure medication therapies, and other variables were extracted. We also examined intervention and comparator characteristics for those studies evaluating a wearable device and collating user experiences.

**Figure 1** Selection of Studies




Flowchart of the selection of studies examining user preferences and experiences from January 1, 2000, to May 26, 2021.

## Data Synthesis and Analysis

Quantitative synthesis of data included tabulation of results and extraction of results by outcome instrument. Descriptive synthesis of all findings by outcome area across all studies (irrespective of design or data type) was undertaken. Meta-analysis of quantitative data was then considered, only if more than 10 experimental comparisons were available for an outcome.

Qualitative analysis of studies was then undertaken, which allowed extraction of themes from qualitative studies and inclusion of free-text comments from mixed-methods studies. A narrative synthesis strategy was then used to organize, summarize, and present the data based on Guidance on the Conduct of Narrative Synthesis in Systematic Reviews.[8] We used a deductive approach to thematic analysis with reference to the technology acceptance model (TAM).[9] Main study findings were tabulated relative to the TAM to summarize the attitudes toward usage and intentions to use, as well as the barriers and enablers across studies and devices. A coding framework was developed by 1 author (N.A.L.) and applied independently by 2 authors (L.P., S.V., or N.A.L.). The beliefs of patients, caregivers, and/or clinicians that technology usage will improve the performance[10] were coded to perceived usefulness, which was represented by constructs including productivity, effectiveness, performance, and overall usefulness of new technology.[11] Perceived ease of use (including easiness to learn, controllability, clarity, flexibility, easy to become skillful, and overall easiness to use of new technology)[9] was also captured, as was attitude, where we coded data that reported the user's evaluation of the desirability of using new technology.[12] The conscious plan to use or not use data or the device[13] was coded to behavioral intention to use, and actual use was also captured, along with preferred features and functions identified through qualitative data.

## Word Frequency and Mapping Analysis

To further contribute to the thematic analysis, full texts of the discussion sections of included studies were analyzed in Python with Gensim 4.0.0 to identify word frequency and word mapping for further data-driven exploration of findings.[14] Terms were given a rank by the summation of their relevance by calculating the term frequency-inverse document frequency (TF-IDF) statistic.[15] The TF-IDF of a term represents its frequency, adjusted for how rarely it is used, and assesses the importance of terms within a collection of documents (in this instance, studies).[16] Bigrams (pairs of 2 consecutive terms) were also examined to supplement the single-term results. In addition, we retrieved key terms related to clinicians, patients, and caregivers and determined which terms associated the most with the medical wearable devices by counting occurrences of terms in the surrounding context of any sentences mentioning these.

## Data Availability

The full data set and statistical analysis codes will be made available on reasonable request from any qualified researcher.

**Table 1** Characteristics of Studies Included in Systematic Review Examining User Preferences

| Study | Population size (n) | Country | Method of data collection | Study design | Novel screening instruments used | Validated screening instruments used |
|---|---|---|---|---|---|---|
| **Beck et al., 2020**[39] | 8 patients with epilepsy | Denmark | In person, semistructured | Qualitative | No | No |
| **Bruno et al., 2018**[17] | 87 (13 caregivers, 22 clinicians, 52 patients with epilepsy) | The United Kingdom | Online, semistructured | Observational, cross-sectional | Yes (RADAR-CNS Technical Survey for People With Epilepsy) | No |
| **Chiang et al., 2020**[25] | 371 (201 caregivers, 170 patients with epilepsy) | The United States | Online, structured | Observational, cross-sectional | Yes | No |
| **Herrera-Fortin et al., 2020**[22] | 392 (171 caregivers, 221 patients with epilepsy) | Canada | Online, semistructured | Observational, cross-sectional | Yes | No |
| **Hoppe et al., 2015**[1] | 102 patients with epilepsy | Germany | In-person, semistructured interview | Qualitative | Yes | No |
| **Janse et al., 2019**[21] | 493 (147 caregivers, 346 patients with epilepsy) | The United States | Online, structured | Observational, cross-sectional | Yes | No |
| **Muchada et al., 2021**[40] | 12 caregivers | South Africa | In-person, semistructured interview | Qualitative | Yes | No |
| **Ozanne et al., 2017**[41] | 40 (15 clinicians, 10 patients with epilepsy, 15 patients with Parkinson disease) | Sweden | In person, focus group | Qualitative | No | No |
| **Patel et al., 2016**[23] | 1,168[a] caregivers/patients with epilepsy | International, multicenter (the United States, Canada, Mexico, Europe, Asia) | Online, structured | Observational, cross-sectional | Yes | No |
| **Quiroga et al., 2016**[18] | 92 (50 caregivers, 42 patients with epilepsy) | The United States | Hard copy, structured | Observational, cross-sectional | Yes | No |
| **Schulze-Bonhage et al., 2010**[19] | 141 patients with epilepsy | International, multicenter (Germany, Portugal) | Hard copy, semistructured | Observational, cross-sectional | Yes | No |
| **Simblett et al., 2019**[42] | 20 patients with epilepsy | International, multicenter (the United Kingdom, Italy, Spain) | In person, focus group | Qualitative | No | No |
| **Simblett et al., 2020a**[43a] | 21 patients with epilepsy | The United Kingdom | In-person, semistructured interview | Qualitative | No | No |
| **Simblett et al., 2020b**[44] | 24 (7 patients with epilepsy, 8 patients with major depressive disorder, 9 patients with multiple sclerosis) | The United Kingdom | In person, focus group | Qualitative | No | No |
| **Thompson et al., 2020**[24] | 27 (7 caregivers, 4 clinicians, 16 patients with epilepsy) | The United States | In-person, semistructured interview, focus group | Qualitative | No | No |

Continued

**Table 1** Characteristics of Studies Included in Systematic Review Examining User Preferences *(continued)*

| Study | Population size (n) | Country | Method of data collection | Study design | Novel screening instruments used | Validated screening instruments used |
|---|---|---|---|---|---|---|
| van de Vel et al., 2016[20] | 155 (114 caregivers, 21 clinicians, 20 patients with epilepsy) | Belgium | Online or hard copy, semistructured | Observational, cross-sectional | Patient and Caregiver Questionnaire, Medical Doctor Questionnaire | No |
| van Westrhenen et al., 2021[45] | 5 caregivers | Netherlands | In person, focus group | Qualitative | No | No |

[a] Examined both user experiences and preferences.

# Results

Of the 935 studies that were initially identified, 47 full-text articles were independently reviewed. Of these, 23 full-text studies met our inclusion and exclusion criteria; however, on rating, 1 study was excluded because it did not meet criteria following quality appraisal (scoring 0%). We therefore included 22 studies in our systematic review. A flowchart depicting the inclusion of studies is presented in Figure 1.

## Study Quality Assessment

Most studies used a cross-sectional design, followed by qualitative methodologies; 1 study used a cohort design. Most studies were of moderate quality, with lower quality rated for mixed-methods quantitative studies which displayed common weaknesses in selection of valid and reliable outcome measures, identification and control of confounding factors, and clear reporting of results. Qualitative studies were of higher quality, with an average rating of 86% (high). Overall study quality was rated as acceptable across all appraisal checklists, with all relevant studies met at least minimal standards of adequacy in accordance with their respective quality appraisal tools. The summary of the results of quality appraisals for cross-sectional, cohort, and qualitative studies is presented in eTables 1–3 (links.lww.com/WNL/C128).

## Study Characteristics

The 22 studies included were published between 2014 and 2021 across at least 14 countries. Collectively, these studies comprised responses from 3,299 participants including 1,245 patients with a diagnosis of epilepsy, 824 caregivers, and 62 clinicians or healthcare workers. One study included 1,168 responders consisting of patients with epilepsy and caregivers; however, the proportion of patients with epilepsy or caregivers who completed the assessments was not reported.

Most studies were observational cross-sectional in design (n = 20), whereas 2 were observational cohort studies. The method of survey administration included in-person/face-to-face (n = 10), online (n = 6), hard copy (n = 2), online or hard copy (n = 1), and telephone (n = 2); the mode of assessment was not reported in 1 study.

Thirteen studies administered novel survey instruments as part of their study design, 1 study used previously validated instruments in their study design, and another study used both novel and previously validated instruments. Seven studies consisted of interviews and/or focus groups, which were administered in-person. Variability in outcome instruments and limited quantitative data reported precluded meta-analysis.

## User Preferences and Experiences

Of the 22 studies, 16 examined user preferences, 5 examined user experiences, and 1 study examined both experiences and preferences. The characteristics of studies examining preferences and user experiences are summarized in Tables 1 and 2, respectively. Of the 6 studies evaluating user experiences, 3 were conducted in an inpatient video-EEG monitoring unit, 2

**Table 2** Characteristics of Studies Included in Systematic Review Examining User Experiences

| Study | Population size (n) | Country | Method of data collection | Study design | Setting of use | Study duration (device) | Device classification | Device | Novel screening instruments used | Validated screening instruments used |
|---|---|---|---|---|---|---|---|---|---|---|
| **Arends et al., 2018**[26] | 33 caregivers | Netherlands | Not reported, structured | Observational, cohort | Community | 2–3 mo | Multimodal | Photoplethysmography, 3D accelerometer | Yes | No |
| **Bruno et al., 2020**[30] | 30 patients with epilepsy | The United Kingdom | In-person, structured interview | Observational, cross-sectional | Inpatient | Mean 6 d | Multimodal | E4 (Empatica) | Yes (Wearable Technology Self-Management Score) | Brief IPQ, TAM Fast Form |
| **Meritam, Ryvlin, and Beniczky 2017**[28] | | Denmark | Telephone, structured interview | Observational, cross-sectional | Inpatient | 24 d–6 y | Multimodal | Epi-Care | Yes (Modified Post-Study System Usability Questionnaire) | No |
| **Nasseri et al., 2020**[29] | 19 patients with epilepsy | International, multicenter (the United States, the United Kingdom, Germany, Australia) | Online, structured | Observational, cross-sectional | Community, inpatient | 3–10 d | Multimodal | Everion (Biovotion), E4 (Empatica), Sensor Dots (Byteflies), GENEActiv (Activinsights), Epilog (Epitel) | Yes | No |
| **Simblett et al., 2020a**[43a] | 21 patients with epilepsy | The United Kingdom | In-person, semistructured interview | Qualitative | Inpatient | Mean 3.1 d | Multimodal | Everion (Biovotion), Bespoke Sensor armband (IMEC), E4 (Empatica), Sensor Dots (Byteflies), Epilog (Epitel) | No | No |
| **Thompson, Langer, and Kinfe 2019**[27] | 20 (10 caregivers, 10 patients with epilepsy) | The United States | Telephone, semistructured interview | Mixed-methods, cross-sectional | Community | 6 mo | Unimodal | Smartwatch (3D accelerometer) | No | QOLIE AD-48, PRCI |

Abbreviations: Brief IPQ = Brief Illness Perception Questionnaire; N/A = not applicable; PRCI = Parent Response to Child Illness Scale; QOLIE AD-48 = Quality of Life in Epilepsy for Adolescent; TAM Fast Form = Technology Acceptance Model Fast Form.
[a] Examined both user experiences and preferences.

**Table 3** Thematic Coding of Qualitative Findings According to the Technology Acceptance Model

| Study | Device features discussed | Perceived usefulness | Perceived ease of use | Attitude toward using | Behavioral intention to use | Actual use |
|---|---|---|---|---|---|---|
| **Arends et al., 2018**[26] | Alarm | | ✓ | | | ✓ |
| **Bruno et al., 2018**[17] | Smartphone, smartwatch, and wristband | ✓ | | ✓ | | ✓ |
| **Chiang et al., 2020**[25] | Not applicable because not within study scope | | | | | ✓ |
| **Hoppe et al., 2015**[1] | Seizure prediction, emergency calls, and documenting registered seizures | | | ✓ | ✓ | ✓ |
| **Janse et al., 2019**[21] | Seizure chance, forecasting range, percent inaccuracy, time burden, location worn, and monthly cost | | | ✓ | ✓ | |
| **Meritam et al., 2017**[28] | Wrist-worn and accelerometer-based seizure detection | | ✓ | ✓ | ✓ | ✓ |
| **Nasseri et al., 2020**[29] | Wrist-worn, high-quality data, and automated measures of signal quality | ✓ | ✓ | ✓ | | |
| **Ozanne et al., 2017**[41] | Seizure activity, monitoring, alarms, and healthcare provider communication | ✓ | ✓ | ✓ | | |
| **Patel et al., 2016**[23] | Sensors for muscle signal, heart rate, and $O_2$ sensor | ✓ | | | | |
| **Quiroga et al., 2016**[18] | Continuous use devices, cell phone alerts, and alerts in less than a minute after detection | ✓ | | ✓ | | |
| **Schulze-Bonhage et al., 2010**[19] | Acoustic warning and visual signal or short message service | ✓ | | ✓ | | |
| **Simblett et al., 2019**[42] | Seizure prediction, healthcare provider communication, manage sleep, manage activity, and detection at night | ✓ | | ✓ | ✓ | ✓ |
| **Simblett et al., 2020a, b**[43,44] | Appearance, wrist-worn and arm-worn devices, raise awareness, reduce repetition, manage data, and provide feedback | | | ✓ | ✓ | |
| **Thompson et al., 2019**[27] | Watch, alarm for SUDEP, and seizure detection | | | ✓ | ✓ | ✓ |
| **Thompson et al., 2020**[24] | Medication management applications that incorporate alarms, reminders, and tracking systems | | ✓ | ✓ | | ✓ |
| **van de Vel et al., 2016**[20] | Seizure detection performance, alarms, and preferences (size of device, electrodes) | ✓ | | | | |

Abbreviation: SUDEP = sudden unexpected death in epilepsy.

were community-based, and 1 was both inpatient video-EEG monitoring and community-based. The average time of wearable use varied across studies from a few days to 6 years.

## Descriptive Findings for Studies Examining User Preferences: Indicators for Assessing the Acceptance and Satisfaction of Wearables

### Acceptance of Wearable Technology

This was assessed in 3 studies. In general, patients with epilepsy expressed a high level of acceptance of wearable technology for management of their epilepsy.[1,17,18] In 1 study, 80% of patients indicated acceptance of use of wearable devices for epilepsy, with the majority (69%) having a preference toward smartphones and smartwatches.[17]

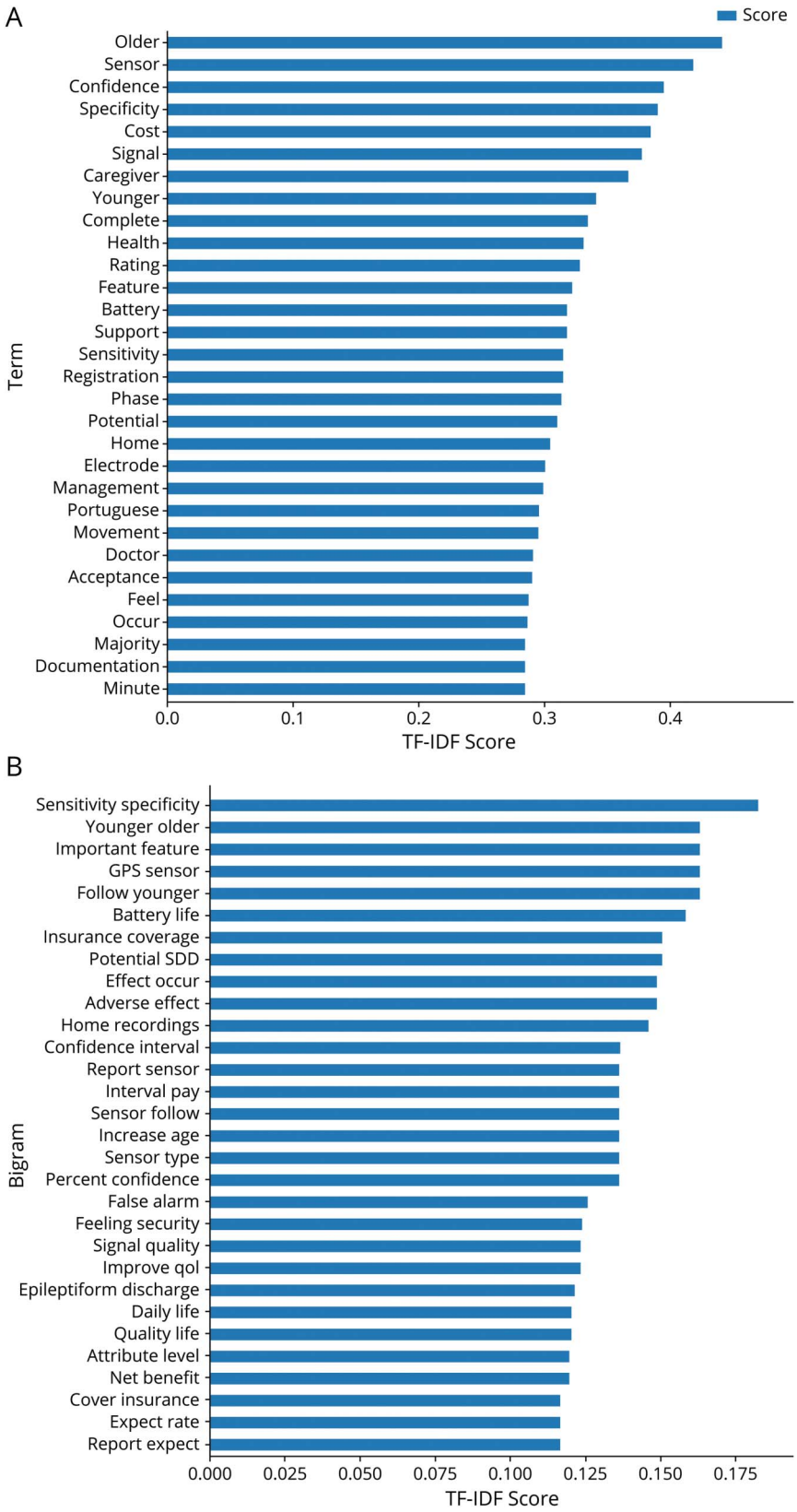
### Accuracy and False Alarms

Reliability of a wearable device was a core theme among studies, including desiring a high sensitivity for seizure detection and low false alarm rate.[18-20] People with epilepsy valued a higher sensitivity (≥90%)[19-21]; higher false alarms (1–2 false detections per week) were more acceptable for patients with higher seizure frequencies (≥1 seizure per week), whereas the acceptable false alarm rate was lower (1–2 false detections per month) in those with lower seizure frequency (<1 per week).[20] In 1 study, higher sensitivity was preferred over lower false alarm rates.[19] Seizure classification of multiple seizure types was desired by healthcare professionals. Real-time detection was also highly desired by patients and caregivers, where most participants desired a short detection window of <15 minutes of seizure occurrence.[18,19,21]

### Cost of Devices and Subscription Fees

Pricing was identified as a substantial barrier for patients and caregivers to own a seizure detection device; between 9.6% and 38% of users had not purchased a seizure detection device due to cost-related factors.[17,22] Potential users were directly

**Figure 2** Analysis of the Frequency of Terms Across Included Studies




(A) TF-IDF across included studies. (B) Bigram TF-IDF across included studies. TF-IDF = term frequency-inverse document.

worried about the affordability and/or the financial burden of seizure wearables. In a US-based study, concern was expressed over whether wearables would be covered by health insurance; 67% of respondents would not use a seizure detection device unless covered by their provider compared with only 6.6% who would use it irrespective of coverage.[18]

Most participants expressed a desire for the wearable device to cost less than USD$300[22,23]; in 1 study, however, this was substantially lower with most participants wanting a preferred low-cost device of USD$50.[21] For a monthly ongoing subscription fee, 43.2% of participants desired this to be <USD$20 per month, 17.8% would pay >USD$21, 38.9% were unwilling to pay a nominal monthly fee, and 11.6% were willing to spend >USD$30 if every seizure was reliably identified.[23] Participants also expressed that they were willing to pay more for an existing device if it could also aid with seizure detection or prediction.[23]

### Device Design

Patients with epilepsy preferred devices that were nonstigmatizing and could be incorporated into everyday objects such as smartwatches or wristbands.[1] There was also a desire expressed by participants to have wearable clothing or jewelry or for mattress sensors.[1] Headbands or hats, cameras, and acoustic-based detection were the least preferred device options among patients with epilepsy.[1,22] Almost half of patients with epilepsy would consider wearing small patch sensors on the chest, shoulder, arm, and neck, but few would tolerate sensors applied to the head or face areas.[1] Implanted devices were the least preferred[1,21]; however, devices or sensors implanted into the body were more acceptable to participants with epilepsy than those implanted directly into the brain.[1] Conversely, caregivers favored more intrusive methods of monitoring, such as cameras and microphones, particularly to address their fear of nocturnal seizures.[22]

Features that patients with epilepsy desired the most included monitoring of sleep quality,[17] mood,[17] concentration,[17] attention and memory,[17] heart rate,[17,20] respiratory rate,[17,20] pulse oximetry, body movements,[17,20] and muscle activity[20]; specifications most valued included long battery life (≥24 hours)[23] and water resistance.[23] Audio/video alerts were also preferred with an unlimited signal range.[20] Device comfort was consistently ranked as important by both caregivers and patients with epilepsy.[22,23]

### Optimizing Care

Improved care was a core theme for patients with epilepsy and caregivers, where most participants felt that wearables would help optimize care.[20,22] Automated and "real-time" alerts were supported by most patients with epilepsy (85%) and caregivers (95%).[22,23] Caregivers expressed that epilepsy patients with frequent habitual seizures would result in greater improvements to quality of care, compared to those with fewer seizures.[22] In 1 study, clinicians expressed an interest in using smart technology to educate caregivers and adolescents with epilepsy regarding their care including information about medications, sudden unexpected death in epilepsy (SUDEP) risk, and women-specific information regarding epilepsy and reproductive health issues.[24]

### Privacy

Patients with epilepsy often expressed concerns that wearables intruded on their privacy. In 1 study, 59.6% were concerned about privacy and confidentiality.[17] Specific concerns included reduced privacy, lack of control over the information, and potential negative effects on their work or their ability to drive.[17] In comparison, caregivers were less concerned about privacy and confidentiality, where only 30.8% expressed concerns about data not being confidential, lack of control over the information, and potential negative effects on their work.[17]

### SUDEP Safety Monitoring

Monitoring of at-risk patients of SUDEP was infrequently discussed with patients with epilepsy, caregivers, and healthcare professionals. In 1 study, heart rate was identified as the most important measurement for both seizure detection and SUDEP interventions.[20]

### Technologic Competency

The technologic readiness of participants was a core theme across multiple studies.[17,20,23,25] Most participants had no previous experience with wearable devices for seizure tracking (78.2%–97.3%).[20,25] However, most participants expressed familiarity with existing technologic devices such as personal computing, tablets, smartphones, Wi-Fi, and smartwatches.[17,23]

## Descriptive Findings for Studies Examining User Experiences: Indicators for Device Tolerance and Use

### Autonomy

Autonomy was a core theme for both patients with epilepsy and caregivers. In a residential study of caregivers of patients who used the seizure detection bracelet, most carers reported increased freedom, but only a minority thought that the patients had more autonomy as a result of device use.[26] In 1 study, child autonomy was improved.[27]

### Comfort

Wearable devices that were already commercially available were found to be comfortable with no substantial side effects.[28,29]

### Device Design

In 1 prospective study that evaluated multiple commercially available devices including 2 wristwatches (Empatica E4 and Activinsights GENEActiv), an armband (Biovotion Everion), and patch sensors (Byteflies Sensor Dots and Epitel Epilog), all devices were positively received.[29] Most participants (75%) demonstrated a strong preference for the wristwatch design, with the Empatica E4 being the most preferred device.[29]

### Optimizing Care

Most patients with epilepsy and caregivers felt that the wearables helped provide optimal and more timely care.[26]

However, only a minority of patients with epilepsy and caregivers reported that wearables reduced the burden of caregiving.[26]

### Mental Health and Quality of Life

Most patients with epilepsy and caregivers who used wearable devices had a reduction in anxiety compared with nonusers.[25] Conversely, quality of life was only associated with minor to nonsignificant improvements with device use.[25,27]

### Usability and Interface

Usability and having an interface that is easy to use was an important theme for patients, caregivers, and clinicians in 3 studies. In 2 studies that examined wearables currently available in the market for seizure detection, most participants reported that the devices were easy to use.[28,29] However, in another study involving 30 patients with epilepsy, which assessed the Empatica smartwatch, only 50% of the participants were able to perform all tasks in relation to setting up and operating the device following a brief tutorial without further assistance; 36.7% required additional assistance, and 13.3% needed constant supervision for at least 1 task.[30]

## Thematic Coding: Technology Acceptance

The elements of technology acceptance deemed by respondents to be important within the qualitative studies are categorized according to the TAM in Table 3, highlighting that the attitudes toward use and perceived usefulness were reported more consistently across qualitative studies than actual use or ease of use. These findings, which are consistent with the TAM, suggest that perceived ease of use influences perceived usefulness and ultimately attitude toward use of devices. The actual use was also highlighted across studies, with mixed-methods designs, where participants provided qualitative information after a period of use being able to provide key insights into both their experience and their preference.

After excluding terms related to study method, TF-IDF identified key terms of "specificity," "cost," and "battery" in the discussion sections of included studies. These single-term results are further strengthened by the bigram results, where the key bigrams of "battery life," "insurance coverage" (finance), "prediction/detection quality" (false alarms and signal quality), and the effect of devices on "daily life" were of greatest importance. Figure 2, A and B presents these term frequency-inverse document frequency graphs.

# Discussion

Wearable devices for automated seizure detection show great potential in improving management of epilepsy. Although this is an emerging field, we identified 22 studies in this systematic review, assessing the preferences or experiences of patients with epilepsy in relation to wearable devices for seizure monitoring and detection with varying study methodologies. We identified several themes that were important to people with epilepsy including optimizing care, accuracy, autonomy, privacy, nonstigmatizing, easy to use, and design. We found that user acceptance of wearable technology was strongly influenced by accuracy, design, and comfort.

We found that a central theme among user preferences of people with epilepsy and caregivers was accuracy, which was discussed as including high sensitivity, low false alarm rates, and "real-time" detection with a short latency period between seizure occurrence and providing alerts. There was a greater emphasis placed on sensitivity, which may reflect preventative strategies for risk reduction and underlies many other important themes and desires identified such as optimizing care. The sensitivity requirements and false alarm rates required by participants are currently matched by the few wearable devices both in trial stages and available in the market, but these wearable devices were only recommended for detecting tonic-clonic seizures.[31] Most desired health features for optimizing care such as seizure prediction, but these features are currently not available for any approved wearable device for automated seizure detection.

People with epilepsy preferred a nonstigmatizing design that could readily be integrated into daily life (e.g., mobile phones or smartwatches). This raises complex psychosocial issues that need to be explored in well-designed studies with appropriate screening instruments to assess the effect of wearables on such factors.

Despite being a significant driver of the need for wearables in epilepsy, SUDEP was rarely discussed with patients and caregivers. SUDEP is common after a nocturnal tonic-clonic seizure,[32] and in most cases, deaths are unwitnessed.[33] Timely interventions may potentially result in risk reduction.[34] In 1 study, nocturnal monitoring using a smartwatch with safety monitoring and a closed-loop feedback system found reduced anxiety in young persons and their caregivers, particularly during sleep.[27] Furthermore, this study found that use of a smartwatch for monitoring was preferred to continuous monitoring with video and/or a microphone to alert caregivers or having someone sleep in the same room because this affects privacy and reduces autonomy.[27] Because most SUDEPs occur in otherwise healthy young individuals with epilepsy,[35] the preferences and user experiences of those at high risk and their caregivers need to be better understood.

Lived experiences are integral to the development of wearables. Most recently, the Wearables for Epilepsy and Research International Study Group proposed recommendations for reporting results from prospective wearable studies aimed at seizure detection.[36] These included obtaining usability challenges and user perspectives from people with epilepsy who wear the device(s). Few studies identified as part of our systematic review examined the preferences and experiences of users. It is disappointing that although the information captured in these studies was informative, there is lack of evidence

of its adoption to improve device design to facilitate overall user acceptance and tolerance.

User experiences of patients with epilepsy and their caregivers were consistent with preferences identified regarding design, where wristwatches were identified as the most preferred design for seizure tracking. In clinical trials of wearable devices, wristwatches, armbands, and sensors were all tolerated well, although there was a greater preference for wristwatches. However, other critical aspects of device acceptance, such as optimizing care or privacy, which were identified as core themes for patients with epilepsy, were not assessed in studies examining user experiences. This may largely be due to most trials being conducted in a video-EEG monitoring unit, where such themes are difficult to assess. In specific devices, the Empatica E4, which is currently the only Food and Drug Administration–approved wristwatch for seizure detection, matched the user preferences of patients with epilepsy in several core areas including device design, cost (including subscription fees), high sensitivity, and providing real-time alerts. However, because it is only approved for the detection of convulsive seizures, it does not meet the desire of healthcare providers in being able to detect multiple seizure types.

The studies with the largest sample sizes used structured or semistructured online surveys to capture perspectives of participants. Although surveys are efficient, they limit responses to predefined questions, affecting the richness of the data collected. Despite having smaller samples, studies that used interviews or focus groups identified a broader and likely more complete range of needs and experiences regarding seizure wearables. Indeed, several later studies used results from these focus groups to construct more comprehensive surveys.

The strengths of this systematic review are that most included studies were of moderate quality or higher. However, there are several limitations identified as part of this study. There are currently no validated tools that comprehensively examine wearable needs and desires in this population. As a result, reported study methodologies were highly heterogenous, precluding meaningful meta-analysis of the findings. This challenge could be partially overcome with the development of standardized and validated tools to measure patient experiences of wearable devices using the themes identified in this study. Studies examining the user experiences of patients with epilepsy were mostly conducted in video-EEG inpatient settings for typically a week, which limit our understanding of the real-world utility of wearables on important themes such as optimizing care, reducing caregiver burden, privacy, technology competency, and autonomy. Most included studies were small and included specific and niche populations (e.g., transition youth) or were biased toward younger adults with epilepsy. Therefore, their findings may not be generalizable to broader epilepsy populations. There are limited data on requirements for children or older adults with epilepsy, who may have different needs and preferences.[37] Although studies were conducted in >14 countries, they comprised mostly individuals from high-income settings and few included patients from low socioeconomic backgrounds who may have different preferences (e.g., cost and design). Several studies did not report whether people with epilepsy or their caregivers completed survey instruments, which introduces further bias. Finally, the word mapping analysis identified terms that were deemed important to authors of qualitative articles, but the terms may not have been directly quoted by the participants in the studies.

In conclusion, this systematic review has demonstrated an emerging body of research examining the acceptance and preferences of consumers (people with epilepsy, caregivers, and healthcare professionals) in relation to wearable devices for seizure detection. Although few studies have explored both acceptance and preference alongside use, findings suggest that device features (including accuracy, battery life, and wearability to permit integration into everyday life) along with cost and ease of use were key themes identified by the authors of the included studies. We expect further advances in disruptive wearable technology, which may contribute toward overcoming these technical challenges.[38] We recommend the development of standardized instruments to routinely measure participant acceptance in future studies and cost-benefit analyses to provide key data for future policy decision making. This will help determine the most effective methods to monitor seizures and improve the lives of people with epilepsy.

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