In their article “Preferences and User Experience of Wearable Devices in Epilepsy: A Systematic Review of Mixed-Method Synthesis,” Dr. Sivathamboo and colleagues performed a review of existing medical literature on the topic of epilepsy. Their goal was simple: to better understand what people with epilepsy and their caregivers want. More specifically, they wanted to know what patients prefer when it comes to wearable devices that could help monitor seizures. Because an accurate record of seizures is essential to epilepsy treatment, seizure monitoring could have a direct effect on patient care and ultimately improve the quality of life of people with epilepsy.

As Dr. Sivathamboo and colleagues state in the article, many seizure-monitoring devices are currently in development. Some are worn like a wristwatch. Others incorporate wearable sensing patches. Some require the patient wear a hat or hatband. Others are implanted either in the body or in the patient’s brain. It is incredibly complex to analyze all factors that may influence patient and caregiver preferences. Part of the challenge is that other studies on this subject do not look at all of the same issues. However, Dr. Sivathamboo and colleagues used several strategies to sift through the data and summarized their findings in their article.

How Was the Study Conducted?

The group performed a systematic review of medical articles published from January 1, 2000, to May 26, 2021. They identified 935 studies and articles that addressed wearable devices for people with epilepsy. They used strict criteria for choosing the articles, one of which was excluding articles about implanted (i.e., not technically wearable) devices. From there, they narrowed the list to 22 articles. In total, there were 3,299 participants: patients, caregivers, and medical health care workers. The articles addressed 3 main topics: user preferences (16 articles), user experience (5 articles), or both (1 article). Although the researchers had looked back over 21 years, the articles that met the inclusion criteria were published more recently, between 2014 and 2021. The articles were from 14 different countries.
Once the researchers had identified the articles they would review, they broke down the data (using a process called data extraction) into several categories, such as accuracy of each wearable device, which devices had a low rate of false alarms, the cost of the different devices, and the devices’ design. They also looked at the demographics of the participants from the studies they reviewed, for instance, the age of the patients, their sex, duration of their epilepsy, type of seizures/epilepsy, and number of medications they were taking. The researchers then analyzed the data, using specific methods useful for systematic reviews of this type.

What Were the Results?

Dr. Sivathamboo and colleagues noted several trends. First, about 80% of participants were accepting of wearable technology. Sixty-nine percent preferred a wristwatch-like device that could be connected to a smartphone. Thirteen of the studies used new study instruments to collect and analyze data. These were not uniform across the studies, making analysis more challenging. Saying this, the researchers found the following:

Accuracy and False Alarms
Across the studies, participants wanted high accuracy and low false positives. Of these 2 factors, 90% of participants valued high accuracy the most. People with high seizure frequency were more willing to accept a higher number of false alarms (i.e., up to 1–2 per week). In contrast, people with low seizure frequency wanted much fewer false alarms (up to 1–2 per month).

Cost
Many of the participants were categorized as high income, which may have influenced how much the group overall was willing to pay for a wearable device. In contrast, 9% to 38% were unable to afford a device. In the United States, many participants wanted their insurance to cover the cost of the device and the monthly subscription fees. Overall, the group was willing to pay up to 300 USD for the device and $20 per month for the subscription fees.

Design
Many of the participants wanted a device that was nonstigmatizing. In other words, if wearing the device would identify them as a person who has seizures, it was much less preferred. For instance, some devices incorporate a hat or hatband sensor: this was less preferred across the group. Comfort was an issue as well. About 50% were willing to wear a patch-type sensor, and some preferred a mattress sensor that could detect seizures during sleep. Most of the participants did not want an implanted device. If an implant was needed, they preferred that the device be in the body as opposed to the brain.

Improved Care
Many people wanted the device to send an alert in real time. Furthermore, they preferred a device that would send an alert in 15 minutes or less. Some were concerned about the privacy of the seizure data: who would have access to the data? Overall, many (85% of patients and 95% of caregivers) felt that having a device like this would improve autonomy. Some studies tried to assess whether these devices affect quality of life. However, there were not many data in this area. The data that were available suggested that a wearable device had no effect or perhaps a small effect on quality of life.

Discussion

Wearable electronic devices are now commonplace. In medicine, there has been increased interest in how to incorporate wearable electronics into a person’s treatment. Because the treatment of seizures is based on the patient’s and caregiver’s report of seizures, a wearable device could be helpful. However, there are few studies that try to assess the types of factors a wearable device should address. Studies like this one help scientists to better understand how wearables could best be used. Many complex issues need to be considered; accuracy, false alarms, cost, comfort, and ease of use are just a few.

With regard to accuracy, participants in these trials identified this as being one of the most important measures of a wearable device. In practice, though, because there are many types of seizures, an accurate measure of all seizure types is difficult. The devices that are available now are best at determining the occurrence of convulsions (also called tonic-clonic seizures). In fact, one of these devices has been approved by the FDA for the detection of only convulsive seizures. This device is inaccurate in detecting other seizure types.

As noted above, participants also wanted devices that were external (i.e., not implanted), easy to use, and nonstigmatizing. Wristwatches were the design of choice. They also preferred devices that could predict seizures, rather than just track them. However, at present, there are no devices that can determine when a seizure is going to happen.

Why Is This Important?

With advances in science and technology, it is easy to expect that there will be many medical wearable devices in the future. Studies like this one are critical. They help us understand the preferences of patients and caregivers with regard to devices like the ones addressed in this study. Devices that are inaccurate, inconvenient, or difficult to use are unlikely to be worn or used. As such, they would be unhelpful as medical devices. Future studies should be standardized, if possible, to consistently measure these concerns. The result will likely be a host of devices that will lead to improved seizure management and treatment and, ultimately, better quality of life for people with epilepsy and seizures.
About Epilepsy

What Is Epilepsy?

Whether we are awake or asleep, our brains are active. Nerve cells in our brains talk to each other constantly. They do this by sending signals and messages to each other. These messages are both electrical and chemical (the chemical messages are called neurotransmitters). Sometimes, for instance, after a brain injury, brain cells send wrong messages. Our brains have their own autocorrect for these messages, but just like with a cell phone, sometimes an error goes through. When a wrong signal is sent, other brain cells respond to the error by sending abnormal signals. If enough brain cells start sending the same incorrect message, a seizure occurs.

One way to think of this is that the brain works like an orchestra. There are different sections in an orchestra, each with its own instruments. Although each instrument plays its own part, it is only when they all play together that complex music is made. One of the ways this happens is that while playing, each member of the orchestra must listen to the other members. As a team, playing together and listening to one another, the best music is made.

However, what if one person began playing a different tune? At first, no one would notice. But soon, nearby orchestra members would become confused: which tune were they supposed to play? As more members of the orchestra began playing the different tune, it would eventually become noticeable. At some point, the different tune might become louder than the original music. This is similar to how a seizure starts and how it keeps going. The brain cells near the cells that are playing the wrong tune start playing it as well, and they encourage other brain cells to do the same thing. Eventually, a person cannot stay aware of what is going on because too many brain cells are busy doing something else: having a seizure.

Epilepsy is not just one uniform illness. There are many kinds of epilepsy. In addition, there are many possible causes of epilepsy. In addition, just as there are many kinds of epilepsy, there are many kinds of seizures. The older definition of epilepsy is that a person has had 2 or more unprovoked seizures in their lifetime. A more modern definition includes that a person who has had 1 seizure and is at high risk of having another.

How Is Epilepsy Diagnosed?

The doctor will need to know as much as possible about what happened immediately before, during, and after a person’s seizure to make an epilepsy diagnosis. For example, how often do the seizures occur? Is there a warning sign? Does the person remember anything about the seizure? All these questions help the doctor to better understand the kind of seizures and therefore the kind of epilepsy that a person is experiencing. Witnesses to the seizure can be crucial to the diagnosis. By asking them to describe the seizure, valuable information can be learned. In instances where patients do not remember their seizure, an observer may be the only one able to provide information.

A description of seizures is critical in determining treatment. In addition, the number or frequency of seizures must be monitored. Are the seizures responding to treatment? Is there a pattern to them? Do they occur only at night?—These observations can help to not only select therapy but also determine when, during the course of a day, that therapy is most needed. Some people do not know when they have had a seizure. This is an area where wearable detection devices can be most helpful. Otherwise, a person may not know whether or how many seizures have occurred.

Medical testing, such as EEG and MRI, is essential to understand the cause of a person’s seizures. EEG is a simple and painless study that records the brain’s electrical activity. The brain waves are picked up by tiny electrodes that are applied to the person’s scalp. Doctors then review the EEG, looking for specific brain wave patterns that happen during or between seizures in patients with epilepsy. These patterns provide critical information about the person’s epilepsy and help the doctors make a diagnosis.

Imaging studies are also critical in understanding the cause of a person’s seizures. The 2 most common types are MRI and CT scans. Modern CT and MRI provide detailed pictures of the brain and are critical in locating tumors, scars, or other abnormalities in the brain that may cause seizures.

How Are Seizures Treated?

There are many treatments for seizures. Medicines are tried first. If they do not work, the doctor may consider special diets, brain surgery, or implanted devices for the treatment of a patient’s seizures. Usually, the physician tries to stop all seizures while causing no side effects. It is important for patients experiencing seizures to tell their doctor about the kinds of problems they might experience while on a medication (or any treatment) for their seizures. Building a strong relationship with one’s doctor is a great way to achieving the best treatment outcomes and quality of life.

For More Information

Brain & Life
brainandlife.org

Epilepsy Foundation
epilepsy.com

CURE Epilepsy
cureepilepsy.org

American Epilepsy Society
aesnet.org

Reference

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DOI 10.1212/WNL.00000000000201236

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