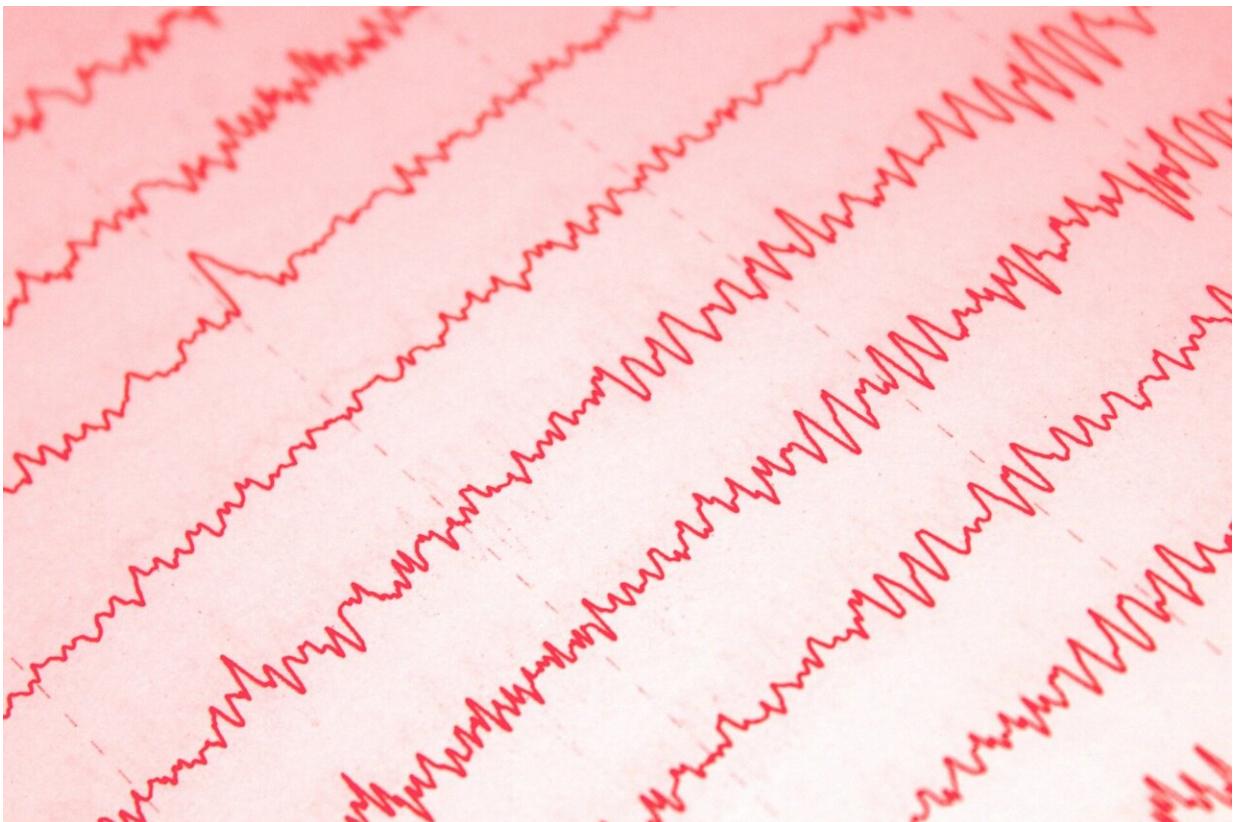


Patients value extended medical interventions—like EEG tests—beyond their clinical use: Study

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For the past 100 years, health care practitioners have valued electroencephalograms, or EEGs, for their clinical use—that is, their

ability to visualize brain activity and to enable the diagnosis of seizures in patients with epilepsy.

Research from Michigan State University shows that while practitioners value EEGs for the information they provide, patients value EEGs in ways that far outweigh the test's clinical utility to practitioners. The findings are [published](#) in the journal *Social Studies of Science*.

"Patients derive [therapeutic effects](#) separate from the EEGs intended diagnostic purpose. Given the uncertainty, trauma and stigma of seizures, patients value having medical experts witness and care for seizures in a comfortable environment that offers opportunities for connection," said Megh Marathe, assistant professor in the MSU colleges of Communication Arts and Sciences and Human Medicine.

"This experience remains with patients far beyond the duration of the procedure and helps them reorient to life with epilepsy."

During an EEG, metal disks, called electrodes, are attached to a patient's scalp. The electrodes pick up the brain's electrical signals and monitor a patient's [brain activity](#) for seizures. EEGs can be ordered for durations ranging from 45 minutes to several days. Marathe's research focused on extended EEGs, where patients are monitored for 24 hours or more.

Drawing on interviews with 25 patients who have epilepsy, Marathe found that patients felt seen and valued while undergoing extended EEGs for the following reasons:

Extended EEGs give underserved patients a sense of agency and reprieve.

During EEG monitoring, patients gain access to material and social

comforts that are ordinarily inaccessible, particularly to women and people with disabilities and low-income status. This helps patients feel a [sense of agency](#) and control in a system that does not appear to value their time.

"EEG monitoring provides women with free time, a rare comfort given the gendered nature of domestic and familial labor. Women value this time of leisure even when deprived of sleep and anti-seizure medication—which they do not take during an EEG in order to induce seizures—even when monitoring does not yield clinically significant data," said Marathe.

Patients have control over food, visitation and activities during EEG monitoring. They can freely order from the inpatient meal service menu, bring their own food and drinks, and have visitors at any time during the procedure. Research from feminist and disability rights activists and scholars have shown this level of patient agency is exceedingly rare in social contexts, according to Marathe.

The generous spatial and technological configurations of EEG patients' [private rooms](#) add to this sense of agency, particularly for low-income patients. Being in a thoughtfully designed space and interacting with new technologies helped one of the patients Marathe interviewed find pleasure during her EEG monitoring experience.

Patients undergoing extended interventions don't always receive private rooms and control over food, visitation and activities. For example, dialysis, a procedure that removes waste and excess fluid from failing kidneys, is conducted in shared spaces that don't permit food, drink or visitors.

"A confluence of technological needs and disease characteristics makes these comforts possible in EEG monitoring," said Marathe. "Private

rooms are thought to improve data accuracy by reducing electrical interference and noise, and [epileptic seizures](#) are thought to be unaffected by food, visitors and other external stimuli."

Medical practitioners consistently watch over and attend to the patient.

EEG monitoring is a period of high anxiety for patients because they undergo this procedure for the express purpose of having seizures en route toward diagnosis and treatment.

"Seizures are unpredictable, recurrent and difficult to experience," Marathe said. "Patients found the presence of the technicians and neurologists to be comforting during the process."

Importantly, patients undergoing EEGs didn't feel surveilled, experimented upon or rushed due to the attentiveness and care of the practitioners.

"Not being rushed is a rare experience in medical settings. Patients are used to medical practitioners not having or making the time to attend to and acknowledge their experiences—one patient equated typical doctor's appointments to the express checkout lane at the grocery store," said Marathe. "That makes the extended witnessing that patients experience during EEG monitoring that much more special."

Patient experiences are acknowledged and validated

Patients are used to being ignored or dismissed in generalist and emergency care settings, particularly when their seizure symptoms differ from mainstream or general symptoms of seizures. In contrast, EEG practitioners are trained to recognize diverse seizure symptoms.

"By locating the pathology within the brain and making brainwaves visible, EEG monitoring places the seizures firmly within the realm of the natural," said Marathe. "Extended EEGs helped patients prove that they are physically ill by displaying the neurological basis of seizures, which distanced the patients from the stigma associated with them."

Patients and caregivers learn how to manage epilepsy.

Extended EEGs provide a forum for patients and caregivers to learn about managing epilepsy from expert practitioners.

"Seizures can be traumatic to experience and witness. Patients and caregivers are often overcome with panic and fear during seizures," Marathe said. "Expert witnessing during EEG monitoring provides the time, space and opportunity for patients and caregivers to learn about seizure response and recovery."

Learning about seizure response and recovery is particularly vital for the patients who have newly begun to have seizures and for the 30% of patients with epilepsy who do not respond to medical treatment, according to the World Health Organization.

Patients feel like they are contributing something of value.

Participants in extended EEGs are often asked to participate in research studies, and the feeling that they are contributing to further knowledge of their condition is empowering to them. In addition, this sense of value is reinforced by teaching patients that all EEG testing results—whether they show [seizure](#) activity or not—are still valuable.

One patient Marathe interviewed underwent an EEG to confirm that her

seizures stopped after a change in medication six months prior to the procedure. Despite the EEG's inconvenience, the patient said it was worth it to get the information and to show her neurologist that the medicine is working.

"Neurologists teach patients to value the EEGs ability to verify patient testimony, even when doing so does not change the course of treatment," said Marathe.

Future implications

Medical practitioners, especially trainees such as residents and fellows, should be taught about the therapeutic benefits of extended interventions, such as EEGs, according to Marathe. Educating these practitioners on the value of empowering patients by providing them with agency and making them feel seen and cared for during these interventions is vital.

Marathe also notes that patients and caregivers should be taught that the opportunity to learn more about their chronic conditions under the supervision of experts is part of the reason to undergo extended monitoring.

Chronic conditions like epilepsy cannot be cured; according to the World Health Organization, 30% of patients continue to have seizures despite treatment and the rest can have seizures due to hormonal fluctuation, stress, sleep deprivation, missed medication, head injuries and infections.

"By providing a controlled environment for patients to seize under expert care, EEGs could be seen as doing the work of therapy. That is, EEGs could be considered just as valuable as treatment, instead of being dismissed as idle time," Marathe said.

Marathe also said hospital administrators and technologists should consider resources and practices that patients value from a therapeutic standpoint, as well as the ones that don't, in reporting for extended medical interventions.

"EEG results are currently communicated via dry, text-based reports that describe the presence and absence of brainwaves and other physiological indicators. These reports could also include information about how patient experiences were witnessed and cared for," they said.

"In [chronic conditions](#), such reports could help normalize the patient's condition and familiarize patients and caregivers with strategies to manage acute events like seizures."

The human element to care is important: Marathe's research, which applies to both digital and nondigital contexts, suggests that patients would not find extended monitoring valuable if automated systems were doing the work of health care practitioners. Therefore, when defining and measuring value, waste and efficiency, practitioners should look beyond readily quantifiable outcomes for benefits that may be harder to estimate.

"In health care, automation requires deciding when the labor of physicians and other human experts generates value over waste and inefficiency," Marathe said.

"Considering patient perspectives and experience, in addition to clinical utility, are imperative to including marginalized patients—especially low-income, disabled and women patients—in debates on automation and the future of health care."

More information: Megh Marathe, Therapeutic value in the time of digital brainwaves, *Social Studies of Science* (2024). [DOI](#):

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