Diagnosis in the digital age: A case for home videos

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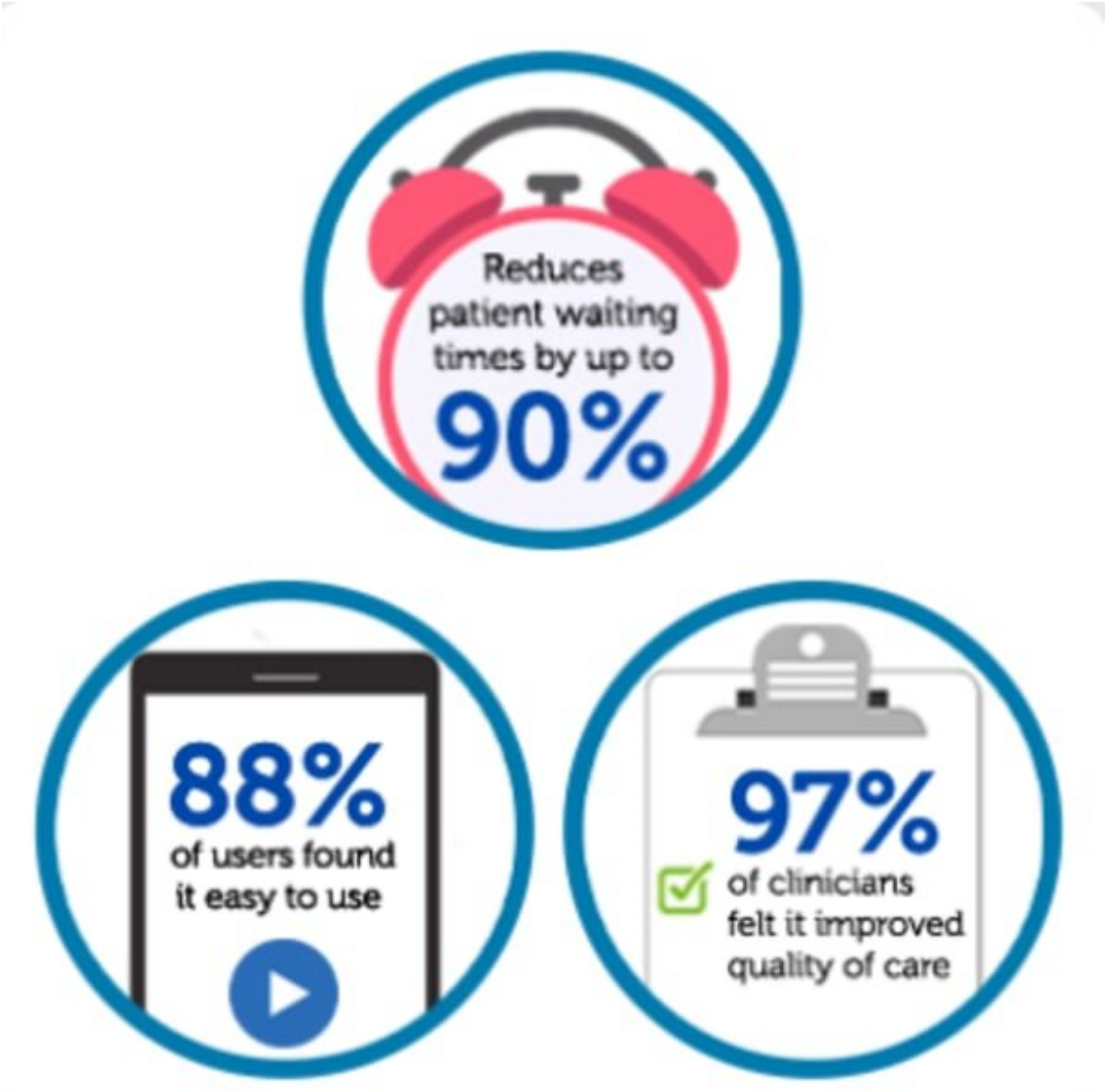

Credit: International League Against Epilepsy

A man in the clinic has had two seizure-like episodes in his lifetime. Selim Benbadis, director of the University of South Florida's epilepsy program, and his resident take a history and complete an exam. They are fairly confident that the man is experiencing syncope.

Later, the man sends them a video taken from a security camera at his workplace, which captured one of his episodes.

"The video—any novice could see that it's clearly a seizure," said Benbadis. "We were wrong. This is the power of video."

Integrating video into the care pathway

Benbadis authored a recent commentary suggesting that stand-alone video should be considered a formal diagnostic tool in the United States, including coding, billing, and reimbursement. But what he is most passionate about is bringing in video as part of the standard of care, with an infrastructure to allow video sharing that protects privacy. The research is published in the journal *Neurology: Clinical Practice*.

Low-resource areas particularly can benefit from the technology, he said. "They don't have the luxury of an epilepsy monitoring unit, or ambulatory EEG," he said. "They rely 100% on history, and history is not all that helpful. Phone video should and can be a part of the evaluation of every patient."

Integrating phone video into practice is more than encouraging families to record videos, said Benbadis; it requires fundamental changes. "Where people present with possible seizures, the reaction of

neurologists is always 'let's order the EEG,'" he said. "But we all know the yield of EEG is low unless you record a seizure. And of course that's what we try to do in an epilepsy monitoring unit (EMU)—but in the real world, it doesn't happen very often."

Benbadis recalled a woman with facial twitching who came into an area hospital on a Saturday. The resident team was concerned about possible seizures and ordered an EEG. The hospital was not staffed for 24/7 EEG; a technologist would need to travel to the hospital and get everything set up. "Realistically, this EEG is not going to happen for at least two hours," said Benbadis.

While the technologist was en route, Benbadis asked the hospital to send him a cell phone video of one of the woman's events. "It's a seven-second video and she has a clear focal clonic seizure of the face," he said. "She didn't need an EEG. The video was free to the health care system, free to the patient, and diagnostic, but I can't put it in the system as a medical test." The patient still had to undergo EEG, which was normal.

"The more we have been using cellphone videos, the more it's obvious that it's an incredible tool with a much higher yield than routine EEG," said Benbadis. "And yet we haven't adjusted; we still do things the traditional way. We need to make cellphone video a medical test."

While video has been used in hospitals for several decades, the use of home video to aid in epilepsy diagnosis and treatment is gaining ground; a recent paper in *Neurology* suggested that home video may be helpful in diagnosing infantile spasms in regions with little to no EEG access.

Home video for movement disorders

Joseph Jankovic is professor of neurology and distinguished chair in

movement disorders at Baylor University College of Medicine, and director of the university's Parkinson's Disease Center and Movement Disorders Clinic. Jankovic has been using video for decades to diagnose and treat movement disorders. His video library includes data from more than 35,000 patients; some videos are taken in clinic, while others are taken at home by family members. The videos are particularly valuable for treating people with paroxysmal dyskinesia, said Jankovic.

In a 2021 article, Jankovic and Andrew Billnitzer found that 95% of home videos from the Parkinson's Disease Center and Movement Disorders Center supported the initial diagnosis. More common diagnoses included functional movement disorders, cerebral palsy, Parkinson's disease, Tourette syndrome, static encephalopathy and Angelman's syndrome. The article also provides guidelines for home videographers on how to record high-quality video.

"In many cases the video confirms what we already knew, but in other cases videos provided clues to cases we didn't really consider," said Jankovic.

He said that videos are extremely helpful for distinguishing functional seizures from epilepsy. "Family members may describe the episode to the clinician but if they take a video, the clinician can see features that might suggest non-epileptic seizures."

A secure platform for video sharing

Sameer Zuberi, a pediatric neurologist at the Royal Hospital for Sick Children in Glasgow, Scotland, has been using home videos to aid in epilepsy diagnosis and treatment since the 1990s. "We used to lend out video cameras and tripods to families to take home in the 1990s, and often by doing that we could get a diagnosis," he said.

As cameras got smaller, families began bringing VHS tapes to the clinic. The advent of the digital era introduced security and transfer issues and the hospital started receiving fewer videos, he said. "You can put a VHS tape in a locked cupboard and catalog it," he said. "What do you do with a 500-megabyte video file? Electronic patient records are not set up for that."

Parents would try to email videos, but the files were too big. Some would set up private YouTube channels or websites where physicians could view videos. More recently, people started using WhatsApp to share videos. These solutions, while creative, were informal and not regulated, and Zuberi notes they likely broke some governance rules in terms of clinical data storage.

A solution to the issue came from an unusual place: The neonatal unit. His hospital's neonatal unit had a service that would allow nurses to take videos on a secure iPad to send to parents, allowing them to see their babies when they couldn't visit the hospital.

"It's a web-based platform. The videos are uploaded to the cloud, and then the families can download them," said Zuberi. "It had to go through all the security and clinical governance required for video transfer, although these are not clinical videos."

Zuberi had a conversation with the consultant neonatologist who set up the system, and they realized they might be able to use the same platform to send videos to the hospital from families with children having suspected seizures. As the COVID pandemic began, Zuberi and colleagues received funding to establish the video system and fund a pilot study. They also received approval to establish a national research video database, which now contains more than 27,000 videos, with about 800 being added every month.

Families register through the web-based platform and provide consent for clinical use, teaching, and research. Families and clinicians can communicate through the platform, and videos can be securely shared with multiple clinicians.

Improving efficiency, fostering communications

The system—called vCreate Neuro—has made care more efficient and economical, said Zuberi. Diagnoses are made in less time, with fewer appointments and tests.

A 2022 report on the system found that among more than 400 clinicians surveyed:

- 99% said the system was useful in overall patient management
- 97% said it improved quality of care
- 93% said it helped in diagnosis
- 92% said it made them feel more connected to patients and families
- 91% said the videos were of high quality and easy to interpret

Among more than 750 families who used the service for their children:

- 88% found the system easy to use the first time
- 64% said it allowed for easier communication with clinicians
- 60% said it made them feel more connected to the clinical team
- Parents felt reassured by the monitoring provided by the system: "Episodes are difficult to explain, or you might doubt yourself about what you are noticing about your child," said one parent. "This makes it easier to have the conversation with clinicians, as they can also see what you see."

Established patients benefit

While useful for diagnosis, the system also can be particularly helpful for established patients.

"If someone with established epilepsy has a new type of event, we ask them to get a video of it," said Zuberi. "Sometimes it is not epileptic—so we think we are reducing medication usage as well."

The 2022 report includes feedback from a parent who uses the system for the ongoing care of her daughter, who has complex needs because of a rare genetic disorder. Prior to using the system, the family would call to discuss any possible seizure activity with the nurse specialist, which "usually meant having to go to an appointment and hope that this behavior happened at the appointment," said the parent.

Now that the family uses the video system, "I'm getting good input from the consultants and the nurse and if she's needing treatment quickly, it's responded to within a couple of days."

International initiatives

The system is now established in nearly all children's hospitals in the UK, as well as all neurology services and district hospitals in Scotland and many district hospitals in England.

"It's spreading to various international centers now, and we continue to work on it," Zuberi said. "We've gotten the whole platform translated into something like 12 languages at the moment, and it auto translates if the patient is using it in a different language than the provider."

International projects using the system include:

- A trial in rural adult epileptology in Germany
- A trial in Edmonton, Canada
- A movement disorders project between the United States and South Africa
- A potential initiative to link a center in Texas with clinics on a Caribbean island
- A potential initiative linking Brisbane, Australia with several Pacific islands that have no neurologists

"The system works really well in high-resource countries, but what I'm really excited about is how we can set it up in areas of the world where there are very few neurologists," said Zuberi.

More information: Selim R. Benbadis, The Best Seizure Diagnostic Tool Is Not a Medical Device, *Neurology: Clinical Practice* (2023). DOI: 10.1212/CPJ.0000000000200117

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