



Going Mobile

Smartphones and other mobile devices can provide real-time information and assistance for people with neurologic problems. BY AMY PATUREL, M.S., M.P.H.

When Evan Moss was two years old, he was diagnosed with tuberous sclerosis complex, a genetic condition associated with epilepsy. By the time he was four, Evan's seizures were doubling every month, peaking at over 350 episodes in September 2007.

"My wife and I quickly realized that we couldn't keep track of Evan's seizures—and the number of times he was changing medications—with a notebook system," says Robert Moss, Evan's father and co-founder of the Web site SeizureTracker (SeizureTracker.com). "It was frustrating, because we were making medical decisions for our son from unreliable information."

It's not uncommon for people with seizure disorders to have a fuzzy recollection of seizure activity. Since patients don't come into the office when they're having a seizure, neurologists have to rely on their patients to provide after-the-fact information.

"People's memories are imperfect," says Neil A. Busis, M.D., chief of the Division of Neurology at University of Pittsburgh Medical Center Shady Side and Practice and Technology editor of AAN.com, the Web site for the American Academy of Neurology (AAN). "If you really want to find out what's going on at home, you need to take down the data when it happens, not months later."

Moss decided to use his computer to record Evan's seizure activity. His professional Web development experience and motivation as a loving parent enabled Moss to fashion an interactive tool called SeizureTracker. The online system allows users to document seizures as they happen, keep track of medication use, and even log medication levels following blood tests.

SeizureTracker can also be accessed by "smartphones" (also called "Web-enabled phones") and other mobile devices that connect to the Internet, through what is called a mobile application ("app" for short). Mobile apps are condensed versions of Internet programs that run on mobile devices.

SeizureTracker has four sections for users to fill in: the header (with the time and length of the event—and an opportunity to add a link to a video of the seizure), the trigger section, the event description section, and a post-event section. The trigger section includes checkboxes like "irregular diet," "bright or flashing lights" and "fever." In the description section, patients check off boxes like "had an aura," and "loss of urine or bowel control." And in the post-event section, boxes include "unable to communicate," "muscle weakness," and "remembers the event."

"We went from a paper logbook—a jumble of notes and

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highlighted codes—to a concise report the doctor could look at and understand quickly,” says Moss. “It streamlined the first 15 minutes of our appointment and helped foster an open dialogue with our doctor.”

MOBILE GOES VIRAL

Evan’s parents aren’t the only ones tracking seizure activity online. SeizureTracker now has more than 7,000 users, with 200 to 300 new users logging on every month. People can even upload videos of seizures, which help neurologists determine which type of seizure a patient is having.

“I think we’re changing the way people are sharing health information,” says Moss. “I also think it’s improving the quality of care people are getting.”

SeizureTracker isn’t the only mobile app available for tracking health information for people with neurologic conditions. My Epilepsy Diary (epilepsy.com/seizurediary), Mood 24/7 (mood247.com), and a variety of other Web sites allow patients to catalogue important health information and easily transfer the data to their physicians.

“We are living in an era where patients have the ability to track and record their own health information,” says Adam Kaplin, M.D., Ph.D., assistant professor in the department of psychiatry and neurology and principal psychiatric consultant to the Multiple Sclerosis Center at the Johns Hopkins University School of Medicine in Baltimore, MD. That includes symptoms such as pain and mood disturbances, which are common in people with neurologic disorders.

“People with diabetes have home glucometers to track their sugars, and those with hypertension have home pressure cuffs to help keep their blood pressure in check,” Dr. Kaplin notes. “But for measurements of health like pain, mood, and dizziness, most physicians still tend to rely on pencil and paper logs.”

“Many of these people are depressed or have multiple health problems, and we’re asking them to recall their symptoms,” says Dr. Kaplin. “That information, as it turns out, is fairly worthless.” As a result, physicians end up making treatment decisions based on faulty information. Alternatively, patients get asked to use paper logs. Unfortunately, only

10 percent of people who are asked by their doctors to keep a paper log actually do so. And the data isn’t particularly useful in terms of making treatment decisions.

But patients who record their mood in real time provide a more accurate assessment of their state of mind than those who try to recall it hours or even days later. What’s more, research shows that 33 percent of people who use electronic devices to record health information will do so when asked to by their physician.

“Ninety percent of the people in this country have cell phones,” claims Dr. Kaplin. “Since this is technology that almost everyone has, how can we not be using it?”

ADVANCING TREATMENT

When Dr. Kaplin discovered that a mobile app for mood tracking didn’t exist, he developed Mood 24/7, a unique tracking system that relies on text messaging to exchange and catalogue health data. Such technology allows people to share valuable information with their doctors without an office visit or a phone call—an attractive feature for patients who have conditions like multiple sclerosis (MS), where depression and mood disturbances are inherent to the disease process. The concept is simple: Every day, at a time you select, you receive a text message asking you to rate your mood from 1 to 10 (1 being terrible and 10 being great).

“One of the most difficult questions to answer during an office visit is, ‘How is your mood?’” says Ben Steinberg, a 42-year-old consultant in Richmond, CA, who was diagnosed with MS in 2005. “It’s hard to give a thorough history. What Mood 24/7 allowed me to do was pay attention to my mood on a day-to-day basis.”

And that helped his physician make treatment decisions. Under his doctor’s guidance, Steinberg started a new medication regimen. After just a few months, Steinberg could see when his mood had improved. He could also pinpoint when there were dips, which helped him open a dialogue with his doctor about what might have caused him to feel more irritable on a particular day.

“The exciting part about this tool is that you have the freedom to decide whether you’d like to track nutrition, exercise, pain, energy level,



Seizure Tracker

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medication use—whatever you think is relevant to your health,” says 34-year-old Jeff Haugh of Maryland, a medically retired special agent for the Air Force and decorated veteran who was diagnosed with MS in 2007. “In that way, it provides you with a clear, concise map of what has been going on over a period of months.”

COMMUNICATION VEHICLE

Many people rely on cell phones to remind them of appointments and to store contact information for their physicians and caregivers. These devices can also serve as portable alarms that prompt people to take their medication. Web-enabled phones allow patients to enter health data on Web sites as it happens and transmit that information directly to their physicians.

Today, mobile devices can even serve as prosthetics for sensory or cognitive impairments. Applications like Speak It! and Lingraphica’s SmallTalk transform text and pictures into speech. The iPhone app Color Identifier assists people who have difficulty seeing colors. Users aim the camera in their iPhone to an object and the phone speaks the names of colors.

Such devices also provide portable video and still cameras for patients’ caregivers to take pictures of events as they happen. If a picture is worth a thousand words, how much might a real-time video be worth?

“Evan started having seizures again last year after being almost seizure-free for two years,” Moss recalls. “We noticed that the seizures looked different than his earlier ones. Using the reports and video-sharing tool on SeizureTracker, we were able to immediately share a video of Evan’s seizure with his neurologist and start a dialogue that resulted in a diagnosis that afternoon: clustering complex partial seizures.”

In circumstances like these, people are able to share information with their health care providers by sending them video of abnormal movements, seizure activity, or other neurologic events. These devices bridge time and space for patients and physicians, facilitating diagnosis and treatment while at the same time redefining the meaning of “point of care.”

However, Dr. Kaplin says, “This is just a tool. It’s not a substitute for a doctor.”

These devices not only provide physicians with valuable information to help guide treatment decisions, but they also serve as a communication device for patients and their spouses or caregivers.

“What Mood 24/7 has done for me is give me some perspective



Mood 24/7

Developed by Dr. Adam Kaplin of the Multiple Sclerosis Center at the Johns Hopkins University School of Medicine, Mood 24/7 allows people to record their mood in real time.

looking back,” says Haugh. “It also promotes a positive dialogue with my wife about some of the things that are difficult to talk about. I think it has gotten my wife involved in my MS treatment—and that has been beneficial for her. She’s even using Mood 24/7 for herself.”

RESEARCH APPS

“There’s fantastic utility in terms of using these apps for clinical trials,” says Dr. Busis. “You can dramatically decrease the amount of money spent on clinical trials and dramatically decrease the time it takes for new drugs to be approved.”

For example, the Women with Epilepsy Pregnancy Outcomes and Deliveries trial (WEPOD) uses technology by Irody, creators of My Epilepsy Diary. After being enrolled in the trial, participants are given an iPod touch

and shown how to use the WEPOD app, which allows them to record medication use, menstruation, and sexual activity. The schedule of visits is programmed into their electronic calendar as well. The mobile app offers researchers a novel way to analyze participants’ daily activity and examine how antiepileptic medications impact fertility.

When combined with social networking technology, mobile apps offer people increased ability to share information about symptoms and treatments. Through online communities such as PatientsLikeMe (PatientsLikeMe.com) and HealthCentral (HealthCentral.com), people can link up with other patients who not only buoy them emotionally, but also offer concrete tips on managing a particular disease. And by openly sharing medical information online, these patients are creating huge health databases.

Of course, these databases are not only of interest to patients and physicians, but also to researchers and advertisers.

So when pharmaceutical giant UCB stepped in and helped PatientsLikeMe start an epilepsy site, no one was surprised. The goal: to learn more about the medications people are using. Sites such as PatientsLikeMe are creating a new health care dynamic in which industry heavyweights pay for access to data that is unavailable anywhere else. In return, patients receive shortcuts to experimental drugs and play a critical role in accelerating research.

“PatientsLikeMe has brilliantly created and combined social networking technology with data collection and tracking and trending of symptoms,” says Dan Hoch, M.D., Ph.D., assistant

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professor at Harvard Medical School and Patients and Caregivers editor of AAN.com. “There’s a lot of emotional support, and the site allows for people to learn from one another what’s working and what isn’t.”

But many doctors and patients remain wary of how this information might be used. Privacy advocates warn that there’s a thin line between patient empowerment and exploitation. PatientsLikeMe shares data with drug companies to get a real-world perspective of how their drugs are doing. They argue that most of the information researchers have on medication effectiveness and side effects are from artificial, controlled studies. These online tracking sites offer a new way of making observations about medications in the real world.

“I have concerns,” says Dr. Hoch, “and there are lots of concerns in the neurologic patient and professional communities. I think the issue is one of trust. Transparency is not one of the strengths of big pharma. I believe there is concern that this kind of data collection is much more likely to be used for marketing than for shortcuts to better drugs. However, if there is a standard and acceptable procedure with appropriate checks and balances, I think many would be willing to give them the benefit of the doubt.”

“Privacy is important,” says Ben Heywood, president and co-founder of PatientsLikeMe, “but it shouldn’t limit our ability to learn from real-world patient experiences and data, because that’s information that will improve patient outcomes.”

With this new technology, patients participating in virtual health communities can even run their own “clinical trials” of a sort. For example, when a scientific study suggested that lithium—a drug typically used to treat bipolar disorder—might slow the progression of amyotrophic lateral sclerosis (ALS, or Lou Gehrig’s disease), 400 PatientsLikeMe members with ALS began taking the drug. Within months, more than 2,000 members—all posting their reactions and blood test results online—were in the experiment, creating the first grassroots, patient-driven drug trial. (See “Hype or Hope?” in the September/October 2008 issue of *Neurology Now* at bit.ly/dUwPDs.)

“The goal of the lithium study on PatientsLikeMe was to report on a trend that was already happening and to help ensure that any

benefits or harms could be identified quickly,” says Heywood.

With data from the PatientsLikeMe study and four traditional clinic-based trials, researchers came to the unfortunate conclusion that lithium does not help ALS patients. Unlike professional studies, PatientsLikeMe shared its results right away without spending millions of research dollars. The Web site is now in the process of publishing its methodology to raise awareness about how health-related social networks can help identify promising treatments that patients are already using experimentally.

However, many in the medical community are concerned about the safety and value of uncontrolled grassroots research and the data it provides.

“The Lithium in ALS experience at PatientsLikeMe is an example of patients experimenting with drugs that are approved for a different indication, which can be dangerous,” says Dr. Hoch. “But if done well, with the guidance of professionals who

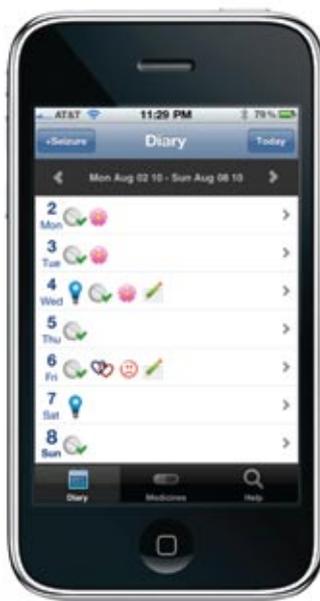
may be among the patients themselves, some useful data can be collected that can stimulate interest in more traditional trials—or decrease interest, as in this case. If the academic world were more accepting of this approach, standards and principles of good research could be incorporated.”

It’s important to remember, as well, that more data is not necessarily better, even if it’s good data, according to Dr. Hoch. “Let’s suppose you’re collecting scads of high-quality data,” he says. “Our present health care system doesn’t know how to deal with that. If you add a metric ton of data from tracking systems or even elaborate portable EEG machines, it adds to the gridlock.”

But there’s no denying that mobile devices and social health networks offer distinct benefits to patients and caregivers.

“As parents, one of the worst feelings in the world is not being able to make something better for your child,” says Moss. “I know we can’t make Evan’s seizures go away on our own, but neither can his neurologist. She relies on hearing about Evan’s seizures to make medical decisions, and Evan benefits when we take an active role in his health care and provide the most thorough information possible.”

If that’s the future of smart medicine, watch for more people to log on. NN



WEPOD Clinical Trial

The mobile app for the Women with Epilepsy Pregnancy Outcomes and Deliveries trial uses the same software as My Epilepsy Diary on Epilepsy.com. The app allows researchers to examine how antiepileptic drugs impact fertility.