

## UNDER MY SKIN

## Lost to Follow-Up

Rosalie hadn't been by in 3 years. Her chief concern was a growth on her forearm. Then she pointed to a cholesterol deposit above her right eye. "I thought it might have been from crying," she said. "My daughter died 14 months ago. She was 26."

I expressed sympathy, and asked if her daughter had been ill. "It's a long story," she said, "but the short of it is that she had a boyfriend who was not a good person. He stored a gun in her closet, and she didn't even know it was there. One night she came home after going out drinking with her girlfriends, other nurses from the hospital. She tripped in the closet, and the gun went off.

"She used to be your patient," Rosalie said. "Maybe you remember—she got those crazy warts when she was in middle school." I checked my records. Her daughter's last visit was in 1996, when she was 13.

In our offices, as elsewhere in our lives, people pass across our line of vision and disappear. We may find out what becomes of them, medically or otherwise, but more often we don't. Sometimes a chance encounter brings their image back into focus, but for the most part, once out of sight they stay out of mind.

This is true not just of patients like Rosalie's daughter who come a time or two for a minor complaint, but

for those we get to know over a sustained period. All at once you realize that you haven't seen them lately, and perhaps never will.

Terry is so familiar that I was surprised to see she hadn't come for over a year. Now past 80, she looked a bit frail but still reasonably hale. I recalled that Tim, her husband and inseparable companion, hadn't come along for her last couple of visits. He wasn't up to it, she'd explained. His mind was getting a little fuzzy. He sent his regards.

This time I asked Terry about him with some hesitation. Dementia, after all, goes in just one direction. "He's doing fairly well," she said. "Lately when Tim sees women on the TV, he thinks they can see him, so he won't undress in the bedroom because he's embarrassed. I tell him, 'Timmy, why aren't you worried that the men in the TV can see me?' But he still won't get into his pajamas until I turn off the TV.

"During the day he's pretty content," she went on. "He just sits there by his radio, all day long. He loves to listen to it and look out the window. He can sit there for hours."

Terry's report jogged my memory of the way Tim looked when I saw him last, an affable gent with a wiry

build and thinning brown hair. He always had a smile on his face, ready to help me reassure his wife, the worrier of the pair. At the end of each visit I would wish them good health and say I was looking forward to seeing them next year. Now that I won't be seeing him anymore, I'll have to picture the Tim in Terry's description, listening to his murmuring radio and gazing out the window as he subsides into his own deepening twilight.

Of course, it's not only patients who are lost to follow-up. People come to the office and tell me they had a physical or biopsy as recently as 2 or 3 years ago but cannot for the life of them remember which doctor they saw. It's not even unusual for someone to come back to me after an absence of a decade or two and express disbelief that they'd ever been here, since neither the office nor its proprietor rang a bell.

When I was starting out in practice, an older colleague told me that once he announced his retirement, his mailbox filled and his phone rang off the hook with messages from anguished patients declaring that they simply would not be able to get along without him. "They did manage, though," he said. "In most cases it took only a couple of weeks."

DR. ROCKOFF practices dermatology in Brookline, Mass. To respond to this column, e-mail Dr. Rockoff at [sknews@elsevier.com](mailto:sknews@elsevier.com).



BY ALAN ROCKOFF, M.D.

## COMMENTARY

## HIT Can Transform Chronic Care

Approximately 45% of Americans live with chronic disease. Despite the fact that these conditions can take an enormous physical and financial toll—or perhaps *because* of the toll these conditions take—patients who live with chronic illness are often the most engaged and empowered patients that physicians see in their practices.

In the health care system of the near future, however, all patients will have to be more engaged in managing their own health, working in tandem with clinicians. As our system moves to a more patient-centered, quality-focused, outcome-oriented model of care, it will be crucial for physician practices and our delivery system to adapt to a new paradigm.

As it stands now, the health care system does not recognize that patients are experts at their personal experience and clinicians are experts at clinical care, each desperately needing access to the information the other has.

To better manage chronic illness, we need a system that capitalizes on our respective expertise and gets patients and clinicians sharing information and talking about what it means. Health information technology (HIT) and personal health records (PHRs) have the potential to play a large part in bridging that gap and in shaping the future of how we give and receive care.

In 2006, the Robert Wood Johnson Foundation created a program called Pro-

ject HealthDesign that put patients at the center of the HIT design process. The goal was to create prototype PHR applications that help people manage their health and guide their decisions. Nine teams worked with chronic disease populations, and all of them found that patients want to share information with their health care providers using technologies that could seamlessly become part of their daily routines.

Since patients with chronic illnesses have to be constantly aware of their health, the project found that patients placed a lot of emphasis on collecting and sharing information that is not typically part of one's medical record. They emphasize information about diet, sleep patterns, medication adherence, and mood, which we termed "observations of daily living," or ODLs.

To capture ODLs in unobtrusive ways, the project aimed to design prototype applications that fit into patients' daily lives. For example, a medication management system application was developed for a cell phone to alert children with cystic fibrosis to take certain medications. A personal digital assistant device was developed to help collect self-reported pain and activity data to provide a fuller picture of patients' everyday experiences.

Capturing this information in real time enables patients to provide their physicians with more specific information about their health. When the doctor asks

a patient about frequency of pain, rather than saying "Sometimes," the patient can use observations from daily living to respond "Yes, almost every day, but less so on days when I go for a longer walk." Another example may be monitoring medications used for chronic pain so that the timing of dosages can be synchronized better with ODLs.

At the end of this year, the project will begin a new round of grants to examine efficient ways for patients to collect and share ODLs in a format that is useful to their providers so that both can make better care decisions.

Already time-strapped clinicians may be weary of an increased role for ODLs, fearing information overload. It is important to note, however, that we are not talking about a Twitter model of patient-provider communications in which individuals bombard clinicians with information around the clock that may or may not be useful. In fact, a more accurate term for the information being collected and shared might be RODLs, or relevant observations of daily living.

The challenge will be finding a way to collect this relevant information, sift through the large amounts of data, and identify what is useful and meaningful.

If this type of information exchange can be achieved, ODLs will become one of the most important tools a clinician has at his or her disposal. Providers will be able to rely on standard clinical mea-

surements and information on sleep, mood, and exercise to better guide patients in managing their chronic illnesses and achieving better health outcomes.

Technology won't transform the health care system, but it certainly can facilitate it. To be clear, integrating PHRs into an office's established patient flow processes will disrupt things in the short term, and it will take an entire team—from physicians to nurses to administrators—to be engaged. However, if we want to move forward and transform our care to a system that results in lower costs, improved efficiency, higher satisfaction, and improved quality, we need to make changes and think toward the future for a stronger collaborative relationship between patients and providers that includes PHRs and HIT.

DR. BRENNAN is the national program director for Project HealthDesign, a national program of the Robert Wood Johnson Foundation, and Lillian L. Moehlman Bascom Professor, School of Nursing and College of Engineering, University of Wisconsin, Madison. DR. JAÉN is professor and chairman of the department of family and community medicine at the University of Texas Health Science Center at San Antonio and serves on the national advisory committee for Project HealthDesign.

The authors disclosed having nothing to gain financially from Project HealthDesign or the prototype designs to track ODLs.



BY CARLOS ROBERTO JAÉN, M.D., PH.D.



BY PATRICIA FLATLEY BRENNAN, R.N., PH.D.