I met Ruth Parker at a women’s health conference in Washington, D.C., last year. She was talking about health literacy, a topic that our own Matthew Grissinger (Medication Errors columnist) has been covering periodically in P&T since 2003. Dr. Parker was mobbed with questions after her riveting (albeit disturbing) talk at the conference, but she graciously agreed to coauthor an article for us (see page 576). In the better-late-than-never department, it occurred to me about a week before deadline that we ought to do a Q&A, a companion piece. Dr. Parker agreed, even though the interview took place during the week when she was shepherding her four kids off to college. To me, this was more evidence of the old cliché that when you want to get something done, give it to the busiest person.

P&T: How did you get interested in health literacy?

Ruth Parker: Almost two decades ago, I (as a clinician educator, interested in clinical research) was working in a large public hospital, Grady Memorial Hospital, in Atlanta. I’ve always liked clinical research and asking questions. I also like working directly with patients and listening to their stories and trying to figure out how we can be more patient-centered in what we do. I was doing something completely unrelated—an unfunded survey of patients in a busy public hospital emergency room. What I found out was how quickly they returned the survey instruments. It was a simple survey, but it should have taken longer than it did to complete.

So I turned to a hospital administrator and said, “Can our patients read?” And he said, “Most of them can.” I said, “What is ‘most?’” He said, “Two-thirds.” I had no idea that a third of our patients can’t read and understand the materials in front of them.

P&T: What kinds of materials, beyond the survey?

Parker: Things like appointment slips, prescription bottles, instructions for an upper GI series, the forms that you have to navigate to be a patient. And I said, “What good are the studies that we do if people can’t even understand the survey instrument?”

I turned to the literature and found that there are a couple of people out there, like Terry Davis [PhD, Louisiana State University Health Science Center–Shreveport] and Barry Weiss [MD, University of New Mexico], who had been thinking about how much of the literature we distribute is written at a level higher than the reading ability of most patients. I worked with a team, including Dave Baker [MD, currently at Northwestern], who was out at Harbor/UCLA Medical Center at the time, and Mark Williams, MD [currently at Northwestern], who was there at Grady. We went into the Robert Wood Johnson Foundation and ended up having studies funded by them that allowed us, for the first time, to go into large clinical settings and measure patients’ health literacy skills. That was back in the early 90s. As we presented that work, people said, “Are you kidding me?” and we said, “No, this is real!”

We went on to take that into Medicare managed care in a large study led by Dave Baker, because we had found that the challenges of reading and understanding and acting on health information were even greater for people who are older; they have a higher disease burden, they have a greater need to understand information, and this is where most of the costs in health care occur. So we replicated the prevalence study in a Medicare population around the country, in four different cities, and what we were finding is that at least one-third of patients (more so among the elderly) have trouble with everyday tasks that we practitioners assume they can do. There’s a big mismatch between what we’re asking patients to do, and their ability to do it.

We and a growing number of other researchers spent about a decade looking at that, looking at associations with chronic diseases, thinking about it—and then, increasingly, the question: what do you do about it? In the meantime, the first IOM [Institute of Medicine] report had come out—I was a member on that committee—and this [topic] was beginning to be picked up by federal agencies, by various states, some health systems, and some professional societies. In 2005, Mike Wolf [PhD, MPH, at Northwestern] and I co-chaired an expert committee for the American College of Physicians Foundation and wrote a white paper that focused on medication labels as an issue at the intersection of health literacy and patient safety. The rubber really meets the road, for patients and consumers, with that label. At the end of the day, you’ve gotta be able to look at that thing and figure out what to do.

We drilled down on the medication label—we had an expert
A Conversation With Ruth M. Parker, MD

We've made some progress. The USP now has a standard for medication labels that came on the far side of that IOM Health Literacy Roundtable workshop summary—that's incredible. That's a huge deal. It was Roger Williams, the head of the USP, who really stood up at the end of our IOM roundtable meeting after our report and said, "We need to do something." Now as you know, they're a standard-setting organization, they don't do enforcing. But it's really important to be able to say there are standards for improved medication labels that didn't previously exist.

I've also done a lot of work with H. Shonna Yin [MD, MS] and her team at NYU, looking at pediatric medications and dosing devices and the markings on them. I mean, isn't it ridiculous that you would have dosing devices with markings that don't correspond to instructions? What I've wanted to do is point that out and then work to build policy that addresses it. That's what I spend a lot of time on. I don't do it in isolation; I work with a lot of wonderful people. I don't see myself as driving it, but I'm an advocate for it.

There are some wonderful, growing partnerships around this. It probably took half a century to get to where we are now, if you look at the history of medication labels. And we're not going to solve it overnight. But the opportunities! To use electronic prescribing, to systematize, and to make the process better—are just sitting there. We're trying to identify the components of a better system and hope that willing partners will step up and make those needed changes.

P&T: Are a lot of these organizations finally starting to work together more effectively now?

Parker: A lot of them are. I think it took us drawing attention to how common the problems are. And I think the IOM Health Literacy Roundtable has been a wonderful group of various stakeholders that have allowed us to present this information and move the agenda forward. The work of the USP has been very important—they had an expert panel that Joanne G. Schwartzberg [MD] and Gerald McEvoy [PharmD], co-chaired; the FDA is engaged and talking about this as it relates to its Safe Use initiative, as the agency looks to see what it can do better.

There have been a lot of willing participants and a lot of people stepping up. It's slow—I can't tell you how frustrating it is to have 50 boards of pharmacy to regulate and to have to work across state lines. I mean, there are huge challenges—and no one voice that can do it all. And we're doing this in a market-driven economy; health care occurs in a market. That's the world we live in. There are many competitors—but we all need to agree that the reason to do this is for patients.

P&T: That's probably the one thing everybody can agree on.

Parker: Exactly.

P&T: I saw that the title of one of your publications—I confess I haven't read them all—had to do with the "epidemic" of limited health literacy. Is that because of the aging population?

Parker: Well, yes, but also—name something that affects this many people. It's not a matter of identifying who those people are—everybody wants information that they can understand and use. The pill bottle label is a great example; how do you know what it means to take one pill twice a day? Or even "take in the morning"—what does that mean? It's not just a matter of figuring out the required reading level for these particular words; it's a matter of how to understand the intention of the person who wants you to take these to make your health better.

How do you figure out what they mean and come to a com-
A Conversation With Ruth M. Parker, MD

mon understanding with them? We need a systematic way to communicate with clarity. Building this health-literate community approach requires everybody linking hands. In America, more so than anywhere I can think of, it’s really embarrassing to not know and understand—it’s hard to admit it. Nobody wants to be the person who doesn’t get it.

P&T: And who can understand a package insert?

Parker: Exactly—but who’s going to walk up and say, “I don’t have a clue what this is about?” And so, why do we have them?

P&T: But it sounds as though you’re optimistic that things are getting better.

Parker: Well, what we currently do is pretty broken. It’s not too hard to make it better. And there are some improvements on the market. Target [pharmacy] and what they did with medication bottles is a good example.

P&T: Tell me about Target.

Parker: This came from Deborah Adler [a designer] who was doing a project back in grad school; they’ve now got bottles with color-coded caps and have also restructured content on their labels, and it’s a different approach. That’s just one example. But you know, as you look at the labels, many have shifted some in the last couple of years. I think that a lot of the manufacturers and dispensers are looking for ways to make things better. Now, here’s what makes me nervous—I’ll give you an analogy: if I’m looking to buy ketchup at the grocery store, I am flooded with options. Size, quantity, volume, price—and that doesn’t really help me in selecting the ketchup. I don’t think we need 50 new and improved labels and approaches to them. If we really want to help patients, we need to come up with a system and to orient patients to that system. And therein lies one of the biggest challenges—we’ve got 50 states and labels governed by their state boards of pharmacy and so many vendors, so many markets.

The other analogy I like to use is red lights; they’re pretty universal. In general, they do a great job in controlling traffic, but they probably wouldn’t if they didn’t all look alike. There’s nothing intuitively obvious about them, but they have a common meaning.

We’ve got people in many institutions looking at this in ways they haven’t before. Brookings Institute has an initiative looking at how to make CMI better; CMI is technically a part of labels. They’re doing that under contract with the FDA. There’s definitely a desire to do better. It’s on the agenda.

P&T: How does the Patient Protection and Affordable Care Act [PPACA] factor into this?

Parker: I think the way we have been practicing medicine in America is not sustainable—the data are clear on that. We’re bankrupt. The PPACA offers a lot of opportunity to make some needed improvements and to also create sustainable and more affordable operations. So I look to it with hope. We’ve got huge challenges—we’ve got a huge population that has not had access to health care. But there is a great opportunity to figure out what to do and how to do it better.

The system has to change. We need good minds, goodwill, and a value-centered approach that helps guide how we’re going to make things better. There are incredible opportunities with electronic systems to improve medication labels—the ability to transmit and communicate electronically and reduce duplicity. What I strongly advocate is the need to use the lens of health literacy—making sure that what we offer patients is understandable, navigable, and clear, and that it meets them where they are rather than trying to retrofit to a system that doesn’t meet patients’ needs. We have an opportunity to build better care models at the front end. What we need are willing partners who can speak with optimism and hope. It has worked in the past, and I think it can again.

Politics aside, the action has to be in good policy. I’m excited!

P&T: On that upbeat note, thanks for your time!