

In Conversation with...Dean Schillinger, MD

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Editor's note: *Dean Schillinger, MD, is a Professor of Medicine at University of California, San Francisco, Director of the UCSF Center for Vulnerable Populations, and Chief of the California Diabetes Prevention and Control Program. His role as a practicing clinician at a safety net hospital (San Francisco General Hospital) has put him in a unique position to pursue influential and relevant research related to health literacy and improving care for vulnerable populations.*

Dr. Robert Wachter, Editor, AHRQ WebM&M: You work in a county hospital with underserved populations, which are very diverse. What are some of the unique challenges of doing patient safety work in that population?

Dr. Dean Schillinger: The overwhelming majority of my work is in the ambulatory setting. One unique challenge that I face in caring for that population in that setting is the degree to which one individual may have multiple comorbid conditions—which in and of itself makes ambulatory management complex. But on top of that are social comorbidities that further confound the management of those conditions. In the context of ambulatory care, in which the patient is the primary driver of safety and 99% of the care is going on at their homes, I'm very happy when I see the patient come back in one piece. One doesn't really know how well prepared patients are to safely manage their chronic conditions at home given those social vulnerabilities.

So, patients bring a lot to the encounter that makes it complex. The most salient and consistent problem I experience as a provider is the issue of communication barriers and the challenges that limited literacy and non-English-speaking communication barriers place on communication in the outpatient setting. That's where I focus my work.

On top of that is the added complexity of the fragmentation of the health care system in safety net settings at public hospitals. This creates an additional degree of jeopardy. We know that well-designed systems can improve chronic care delivery and, in the inpatient setting, well-designed systems can improve safety. The reality in public hospitals is that our systems are not terribly well designed to consistently give providers information when they need it. I recently took care of a patient for whom somebody ordered a foot film, and I hadn't been alerted that there was a fracture. I was seeing the patient in follow-up and, lo and behold, I

was neurotic enough to be checking through the computerized system and found this abnormal result. So, public hospital systems are disadvantaged by being relatively resource poor, and we don't have the kind of systems that can enable providers to take care of a complicated cohort of patients in a longitudinal fashion.

RW: Let me shock you by telling you that story would not surprise anybody if it happened here [at UCSF Medical Center, an academic teaching hospital].

DS: Exactly. The difference is, in that setting, if a patient was thinking "my foot's hurting a lot, somebody ordered an x-ray, and I haven't heard back," the patient might actually try to find out what happened with the test result. Public hospital patients, for the most part, are disempowered and may be used to having problems with access to care, so it didn't even cross her mind to actually be proactive about searching it down. The real target of the Joint Commission's "Speak Up" campaign has got to be the public hospital patient, because this patient would never have spoken up to overcome the failures we have in our system.

RW: Regarding the ambulatory environment, you said that 99% of the care happens beyond our view. Most of the initial work in patient safety was in hospitals. How does this recognition that most of the action happens outside of these institutions change the way you approach this problem?

DS: First, we need to get a better handle on the kinds of patient safety issues that are happening in the home. We elicit some of them during the encounter. But many of these are so commonplace that we don't even reflect on them and we don't bring them to the attention of thought leaders in the patient safety movement. Thinking again about my clinic yesterday, there were about a dozen issues that came up that represented potential adverse events or were adverse events. But think about the number of times that we do medication reconciliation in the office and we pick up some pretty scary things. We often just say, "Yep, this is San Francisco General, we see this." But we don't really quantify, document, and develop systems interventions for that. So, number one is to be more self-aware and see the outpatient encounter as a point of inter-visit surveillance.

Second, we need to prioritize patient safety more than we do now in the kinds of decisions we make in the office encounter. We are very well trained to think about clinical practice guidelines. In the pursuit of maximizing quality, though, particularly in the public hospital context, we may be unwittingly jeopardizing patient safety because we're not building in safeguards. Whereas it may be the right thing, for example, to ramp up the methotrexate on a patient who has rheumatoid arthritis and a score of 6 out of 10 on their pain scale, we need to ensure that the patient knows the adverse effects of methotrexate, is well-prepared to recognize symptoms of infection, and reports those symptoms early rather than late. They need to know that they need to come back to get their liver function testing, or we need to have a system in place to proactively trigger liver function testing. Until and unless we do that, I worry about intensification of medications, particularly high-risk medications. We have done a reasonable job of doing that for anticoagulant care, but our research has shown that even this condition is fraught with problems. So the whole dynamic between medication intensification, the pursuit of quality, and the risks to patient safety needs to be reconciled when there's a black box medication involved.

RW: Can you describe what the health literacy field is about?

DS: The Holy Grail pursuit is to identify a measure that can capture the degree to which an individual has the capacity—probably a dynamic capacity, not a static capacity—to understand medical instructions and act on them in a way that is consistent with their own values and optimizes their health. The way that has been operationalized is to measure a patient's literacy levels as they relate to health care instructions. That's obviously not a perfect measure but, as it turns out, individuals' literacy levels—as they relate to health care materials—tend to be fairly robust predictors of a whole bunch of things. So it's been a good enough surrogate measure for the larger construct.

RW: The construct appears to be, do they understand the physician's instructions? This doesn't necessarily reflect whether they are comfortable and empowered to speak up if they perceive something as not being right. I imagine those two are conflated a fair amount. But are they different topics?

DS: I think that the IOM [Institute of Medicine] definition, which was focused on understanding instructions, is a more narrow view. When you talk to the average person in public health or clinical care, they're thinking of a much larger construct—which includes oral communication, skills and tendencies, and understanding of oral communication, written communication, and Web-based communication as well as the ability to advocate for oneself in a whole variety of dimensions—and that is a very complex, multidimensional construct. The current measures don't even approach that. That said, if someone has limited literacy skills, we and others have shown that it is a very strong predictor of not speaking up, or of not being able to accurately describe your symptoms, for example. It turns out that the more narrow measure of literacy does tend to be correlated with these other dimensions.

RW: What's the interaction between the field of patient safety and the field of health literacy?

DS: The connections are most apparent when you think about ambulatory care and transitions in care, wherein the patient and family need to be a critical or central part of the health care. The whole concept of patient-centered care is that the patient is at the center of her care. So the obvious overlap is that if patients are not well enough prepared, either because of their educational attainment or because of a poorly run health care system that doesn't support patients to learn about their conditions, they could be at a greater risk of adverse events occurring in the home. Until recently that was an open question. Increasing research now supports that there are indeed overlapping Venn diagrams between health literacy and patient safety in the contexts of ambulatory care and transitions in care. The other parallel is that those of us in the field of health literacy have tried very hard to describe health literacy as a systems problem. Recognize that about half of the population in the United States has [literacy skills below the level](#) that has been deemed adequate for health care. Well, it cannot be that 50% of individuals in the United States have a problem. It must be a systems issue. Patient safety recognizes that it is a systems issue, but the actors are individuals who are prone to error. I think those two are the clearest parallels.

RW: You mentioned that half of the U.S. population has health literacy levels below adequate. What other facts in the field are surprising or interesting?

DS: One of the most important facts came from a prospective UCSF study that showed that inadequate literacy skills are associated with a doubling of the risk of mortality. In terms of its implications for safety, probably the strongest evidence is around the issues of medication reconciliation and medication-related

adverse events, wherein it's very clear that patients with inadequate literacy skills have probably double the likelihood of not knowing how to take their medications and not knowing what their medications are for. They also have a doubling of the likelihood that they're actually taking it incorrectly as measured by intermediate markers like INR [international normalized ratio] tests for warfarin, or hemoglobin A1C for insulin. This has been well-studied with respect to [insulin](#) and [warfarin](#).

RW: What have we come to learn about measuring health literacy?

DS: As many as two-thirds of people with chronic diseases have limited literacy skills. Given the prevalence of the problem, particularly if one is working in a public hospital, I don't advocate for direct measurement or screening. Rather, we just say that this is the rule: Let's assume that everybody has it [limited health literacy]. That way, it is sort of a "universal precautions" equivalent in the patient safety movement. Even if a patient has adequate literacy skills, some of the interventions that we're recommending would be very welcome. So there is really no downside to doing careful medical reconciliation, making sure that the patient can report their symptoms and reliably understand the side effects of their medications.

RW: What do we know about interventions? Which might you do with all your patients?

DS: Let me start with the individual patient. When I think about the visit, I think about the two-way communication that takes place. We often jump to thinking about how are we going to speak more clearly and more nicely to the patient. But the *elicitation* portion of the visit is particularly important with lower literacy patients. If we're focusing on chronic disease, we need to clearly and accurately elicit patient symptoms. For a patient with heart failure, this means making sure I really understand whether this person has moved from class II to class III, or is he still class I? Because that will drive the management decisions and the associated education. It's important to be very careful to elicit symptoms and elicit patients' understanding of their medication regimens, particularly with high-risk medications. Certain techniques can be used to do this more reliably and consistently from one patient to the next. But simply asking patients if they're taking their medications and doing an adherence kind of questionnaire may not be enough when really you're looking for understanding as well as adherence. For example, are you taking the warfarin the way I think you're taking it? That elicitation communication needs to be focused on.

The second is being aware of when we are teaching new concepts to patients and trying to ensure that the patient has understood and integrated that information and can actually carry it out at home. The techniques that have been shown to be beneficial and efficient are the so-called "teach-back" method or "teach-to-goal" method. The teach-back method is simply asking patients to report, in their own words, what they're going to do with their diabetes medicines when they go home. Or ask, "When you go home and your grandchild asks you what the doctor said about your heart, how are you going to explain this to your grandchild?" It's really designed to explicitly elicit the patient's perspective on what was just taught. As opposed to asking the patient, "Do you understand?" or "Was I clear?", because then the patient is almost universally going to say, "Yes, that was great." Others have tried to expand this concept, particularly for health education efforts, into what's called the teach-to-goal method: one goes through these teach-back loops until the patient has actually mastered the learning goal. Whatever the goal is, the idea is to determine that goal *a priori* and use the teach-back until the patient can get as close to demonstrating

mastery as possible. These efforts do not take a lot of time, but they are very high yield.

The third communication technique is to eliminate jargon during the visit. We and others [have shown](#) that doctors and nurses, genetic counselors, you name it, any health professional, tend to teach and communicate using medical jargon. Limited literacy patients are the least likely to understand such jargon and will almost never challenge the clinician to clarify. So eliminating jargon from the lexicon—recognizing that we speak two languages and trying to speak simple English—can be very helpful.

The next few are more system-level interventions, which may or may not be actionable at the individual provider level. The first is the idea of employing more robust health education vehicles. We rely on me talking and the patient remembering, or me giving out a brochure and the patient reading it. We really need to start developing more robust electronic communication platforms for visual communication. This has been studied in chronic disease care and anticoagulation care, and it can really improve safety.

The other systems intervention is for us to be thinking about the period of time between visits as an opportunity to be proactive before patients fall through the cracks. We've been doing it with automated telephone systems, but one can imagine that simple technology solutions could be used to engage patients between visits. And this can be done at a very low cost to the health care system, particularly as one scales it up.

RW: What are the levers to get systematic changes in place?

DS: Patient safety is a lever. When we do root cause analyses here at San Francisco General, particularly the few times they come up in the context of ambulatory care, it's almost always physician–patient communication that is at the root cause. The second is malpractice claims. The overlap between health literacy and patient safety has gotten me in the room to talk to hospital CEOs about health literacy when otherwise they would have little to no interest in it. The financial issues have been largely unexplored. There have been some attempts to try to quantify the costs of limited health literacy in terms of rehospitalizations. But they have not been very robust studies, and a lot of the potential benefit depends on the financial incentives placed on the health systems to determine whether or not that's cost-saving or cost-making. The other lever is that caregivers are frustrated by a system that is perfectly designed to make them not understand what they're supposed to do. This last one ultimately must be the driver of change.

RW: How can public reporting and incentive techniques from the policy, safety, and quality worlds be applied to health literacy?

DS: If we can identify best practices and then use incentives to implement some of those best practices, that would be great. Of course, as a public hospital clinician, I'm always wary about using incentives because our patients have greater difficulties navigating and understanding the system. One would have to be very careful about recognizing the ways in which patients with limited literacy skills are inequitably distributed across different health systems and accounting for that, as is done in the United Kingdom. But otherwise it could be an appropriate lever.

The last lever is health IT. Health IT can go one of two ways with respect to this health literacy issue. It could either exacerbate the problems because we're developing health IT interventions that really require

patients to be very familiar with high tech to be able to understand how to use it and benefit from it. On the other hand, we could see the health IT revolution as a solution to the health literacy problem if, and only if, we involve lower literacy patients, and the health systems that serve them, in the development of the interface and the interventions themselves.

RW: Can you give an example of how changes in regulation or accreditation could help promote a best practice in health literacy?

DS: Currently, there is proposed legislation in California that aims to fix the pill bottle. It may seem silly, but the variation of labeling that goes on with pill bottles occupies probably 80% of my visit and creates 80% of my patient's confusion. So developing standards and verification tools for prescription labels or prescription labeling systems is important. I'm not saying it needs to be a one-size-fits-all solution. Different health systems can develop them differently, as long as the labels have some standard features, which have to have been well tested and validated in these populations. Particularly if you focus on high-risk medications, I think this could move the needle a little bit in terms of safety.

RW: One challenge is engaging patients without necessarily blaming them. On the other hand, I wonder, is all the responsibility on the side of the providers and the systems? Or do patients themselves have some responsibility? How do you think that whole tension through?

DS: I don't see it as a tension at all. Absolutely, the whole premise of chronic care is that almost all of the responsibility rests on the patient and family. The question I'm trying to raise simply is, to what extent do we enable and prepare people to take on that responsibility? It's not dissimilar to the goals of education in general. My son is now in elementary school, and we would like his education to prepare him to be autonomous and responsible when he's an adult. Not to infantilize patient care and say it's about K through 12 education—but the model of health care and chronic disease care is about education and empowerment. It's about preparing people to do a good job for themselves and for their families, and to enable them to know how to access resources appropriately to help them when things go awry in their chronic disease. I believe it's a shared responsibility.

RW: Can you talk a little bit about the issue of informed consent and how it interacts with the challenges in health literacy?

DS: It's now very well established that the informed consent process (whether it's informed consent for research or informed consent for surgical and medical procedures) is not perfect for everybody and is particularly imperfect for those who have limited health literacy, for the reasons that we talked about before. Moreover, informed consent often is a rushed and almost robotic process that we go through to get done what we think needs to get done. Individuals with limited health literacy are more likely to leave an informed consent discussion not knowing what the procedure they just agreed to involved; or what the risks, benefits, tradeoffs, and alternative treatments might involve; and most importantly, what they need to know and think about with respect to the future after the procedure is done. This does raise some concerns, not only about quality and trust in the health care system, but potentially about patient safety. When you think about the Speak Up campaign, we need folks to report to us when they don't understand these essentially critical discussions.

