Tackling Low Health Literacy Among Primary Care Patients: A Model from Missouri

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Carla Zema
Welcome to the Agency for Healthcare Research and Quality’s CAHPS User Network podcast series on improving patients’ experiences with care. I’m Carla Zema from St. Vincent College and consultant to the CAHPS User Network.

Today, we have with us Stan Hudson, Associate Director for the Center for Health Policy at the University of Missouri. He serves as an active member of the Health Literacy Missouri Coordinating Council and is also Chairman of the Health Literacy Education Committee. Health Literacy Missouri is a collaborative effort to improve health literacy.

The quality improvement, or QI, podcast series began with a discussion of why improving patient experience is so important. We then talked about some of the factors that are important to any quality improvement effort such as organizational culture, leadership, and teamwork. Next, we gave you an overview of starting improvements of patients’ experiences. Now we are presenting specific strategies for improving aspects of the patient’s experience. Stan is with us today to tell us about a specific effort in Missouri focusing on helping providers to improve the patients’ experiences for those with low health literacy. Thank you so much for joining us today, Stan. Can you start by telling us a little bit about Health Literacy Missouri?

Stan Hudson
Yes, Health Literacy Missouri is an initiative that was started five years ago by the Missouri Foundation for Health, which is a local conversion foundation here in Missouri. They began by funding three resource centers across the state that were focused on various aspects of health literacy, and one of the resource centers was us here at the University of Missouri. And, we focused on developing educational programs to target health literacy
and mainly those for health professionals and providers that are out in practice and also those in training, so students.

About a year ago, Health Literacy Missouri actually moved out on its own and became its own 501(c)(3) non-profit entity, and so now it is overseeing all of the health literacy activities in the state and providing kind of a coordinated effort across the state to improve health literacy and then also starting to disseminate some of our programs nationally.

**Carla Zema**
Great, sounds like an impressive initiative. So how does Health Literacy Missouri view or define health literacy?

**Stan Hudson**
Well, that’s a good question, Carla. Health literacy is, you know, really hard to define. In fact, the definition has kind of gradually been evolving over the years. The original definition you often see cited states that health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions and that’s a very static definition that places the responsibility largely on the patient.

And so since then, that definition has kind of been expanded to encompass a more holistic view that includes the responsibilities of the health system. And this expanded definition moves beyond providing just a static explanation and can more serve as kind of a behavior change model to actually improve the quality of care in the patient experience. And so to be honest, at Health Literacy Missouri and at our MI Center for Health Policy here we try not to focus on the definition so much because that can confuse people. What we do know is that what is very easy to recognize is that there is a clear gap in health literacy.

The average American reads between a seventh to eighth grade level and comprehends the information that they read between a fourth to seventh grade level. Yet most health information, whether it’s spoken or provided in a written form, is at a tenth grade level or higher. So, there’s a clear gap in the patient’s abilities and the way that the health system is providing information to them. And so we focus on reducing this gap between this complex information, the demands of the health system, and what patients and families are able to do.

And so we focused a lot of our trainings on system and practice improvements that provide a more universal approach, that not only improves the health experience for those with low health literacy but for all patients and their families.

**Carla Zema**
That makes a lot of sense. It’s really important to think about health literacy from that expanded definition so you can think about it in a way that defines it as something that you can improve versus a characteristic of the patient that the provider can’t do anything about. So how are you going to measure this broader definition of health literacy or the broader concept of health literacy?

**Stan Hudson**
Well from the system perspective, we were struggling with this for quite a while. You know, there are very few, well there were no, validated survey instruments that specifically examined health literacy issues, and you can conduct from a system perspective what are called environmental assessments of hospitals or clinics and there are great tools out there, such as those developed by Dr. Rima Rudd at Harvard, and they can provide a full
assessment of how well a facility is doing in relation to health literacy. However, they’re very extensive. They examine everything from oral and print communication to patient way finding and navigation, and they even look at some of the clinic policies to see how those may impact health literacy and patient understanding and communication.

And as such, they take a lot of resources and commitment from the facilities, and as you know, many of our health facilities right now are already overtaxed with the demands of transitioning to electronic health records or restructuring for future reimbursement through either patient-centered medical homes or accountable care organization models. So, we need to make it easy for them. They won’t be able to conduct those sorts of environmental assessments on an ongoing basis so that they could establish trend data. They just don’t have the resources to do it right now.

But fortunately for us, the CAHPS group, you know, developed and released their supplemental Health Literacy Item Set for their Clinician & Group Survey last year, and it includes 29 supplemental items that were specifically designed to address health literacy issues from the patient experience. And so, we see that as kind of the way to go where you can really understand how health literacy is being perceived by these patients in the practice.

**Carla Zema**
Great, we’re so glad that you find those items useful. Can you tell us what Health Literacy Missouri is going to do to address the health literacy of the system?

**Stan Hudson**
Yes, we’ve developed a practice improvement module for physicians, which provides simulation training and health literacy coaching to assist physicians in developing and implementing a health literacy plan for their practice or clinic. So physicians will come and they’ll take a small training with us for a day and then we’ll do some health literacy planning and then they go back to their own practices, and they take some baseline measurements, they implement their plan, and then they take some additional measurements six months and 12 months out to see if they’ve had any practice changes based on the implementation of that plan.

**Carla Zema**
Great, what does the intervention entail?

**Stan Hudson**
Well, it involves a full day, sort of workshop in which the learner, the physician learner, participate in peer learning discussions and simulation training in the morning. And that simulation training takes place with, you know, actors who are trained to act as patients. It takes place in a real simulation lab. It’s the real clinic setting that they are used to but it’s in a shame free, non-threatening environment so they can practice some of those techniques and things that we give them.

After that, we sit down with them with we have what are called health literacy coaches who then introduce the *AHRQ Health Literacy Universal Precautions Toolkit*, which is a great resource that was introduced to try to create kind of practice change around health literacy. And using that toolkit, we helped physician learners formulate a basic health literacy plan which involves up to three or four of those tools and then they go back and they implement that in their clinic.
Great, so that gap in health literacy transcends all settings of care. Are you just working on the ambulatory side or what other types of providers are you working with?

Currently right now, we’re just focused on the ambulatory side. We recently had our program approved as a maintenance certification program for the American Board of Internal Medicine. So we’ll begin offering the health literacy practice improvement module to internal medicine physicians in August, mainly ones in Missouri to start out. Then we hope to expand the program to other boards in the fall beginning with the American Board of Family Medicine and the American Board of Pediatrics to make it available as part of board certifications for other primary care physicians beginning in 2012.

You know, one of the limitations is being able to measure this and right now the CAHPS Health Literacy Item Set has only been validated for the Clinician & Group set. So as they are developing other item sets for other CAHPS surveys and so as those other surveys are released and validated, then we’ll be able to move this into other settings as well.

Great, so what’s your plan for measuring the result?

Well, what we plan to do is once the health literacy coach and the physician have finalized the health literacy plan that they wish to implement, we give the physician an abbreviated survey for them to take back to give to their patients and that abbreviated set includes some standard demographic data, you know, collecting information on race, age, et cetera, along with a subset of general health literacy questions that comes from the CAHPS Health Literacy Item Set, and these will be contained on all the surveys that we give to all physicians so that we have some comparison data, but in addition to that, we’re going to identify some additional probably three to four items that are specific to techniques or issues that the physician chooses for their plan.

So for example, if a physician wants to incorporate the teach-back method, which is one of the evidence-based health literacy techniques that we use -- it’s something that you use to assess how well a patient understood their instructions and knows what to do when they leave the office -- then what we would do is we would include the CAHPS supplemental item set. There’s one item in there that specifically asks, ‘In the last 12 months, how often did this doctor ask you to describe how you were going to follow these instructions?’, and so we would include that on all of the surveys for those physicians who would be interested in incorporating teach-back as part of their plan.

And so there will have some differences in what the surveys are, but those will be very tailored to what the physician wants to do in their practice so that we can try to track those improvements. You know, we found the CAHPS Health Literacy Item Set to be very useful. The patient perceptions to us are paramount in examining health literacy. For example, a study released in the Archives of Internal Medicine last year found that over three-quarters of physicians, about 77%, believe their patient knew their diagnosis; however, when they asked the patients, only slightly over half, or 57%, of patients actually did.
So even though physicians and clinicians and things may think they’re doing well at health literacy, if they don’t really measure those patient perceptions, they’re not going to really get a true measure and know that. As far as we’re concerned, there’s no better way to measure the patient experience than through using the CAHPS survey. And so we’re really looking forward to release of the future health literacy item sets for say the Hospitals CAHPS and the Health System CAHPS as these will be very useful as we move into those settings.

**Carla Zema**
Great. Well thank you so much Stan for sharing your expertise with us today. This podcast was a little bit unique in that you’re really in the process of rolling out this intervention. Normally, we brought you interventions that have been already rolled out and measured. We felt this one was so important to highlight because it brought together all of these evidence-based interventions, such as the *Health Literacy Universal Precautions Toolkit* and AMA’s *Health Literacy Toolkit*, as well as this program being part of ABIM’s maintenance and certification. You really have put together a very impressive statewide effort as part of Health Literacy Missouri, so we thank you for bringing that to us today.

**Stan Hudson**
Well, thank you, Carla.

**Carla Zema**
If you’d like to learn more about the CAHPS item set that addresses health literacy, you can also access a Webcast that was presented on April 5th of 2011 entitled “Using CAHPS Item Sets that Address Cultural Competence and Health Literacy.” You can download all of the podcasts in this series as well as the Webcast I mentioned previously at the CAHPS User Network Web site at [www.cahps.ahrq.gov](http://www.cahps.ahrq.gov). That’s [www.c-a-h-p-s.a-h-r-q.gov](http://www.c-a-h-p-s.a-h-r-q.gov). For more information on strategies to improve patient experience, check out the CAHPS Improvement Guide on the Web site.

This guide has a lot of useful information from planning a QI initiative, all the way to specific strategies that you can use. You can also access other QI resources such as case studies detailing the use of CAHPS survey results. The CAHPS User Network also offers free technical assistance and can be reached by calling the CAHPS helpline at 1-800-492-9261 or via e-mail at cahps1@ahrq.gov, that’s CAHPS, the number 1, at [@ahrq.gov](mailto:cahps1@ahrq.gov). We thank you for joining us and we look forward to bringing you more stories and experiences from users of CAHPS survey.

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