Indian Health Service
Division of Diabetes Treatment and Prevention
Leading the effort to treat and prevent diabetes in American Indians and Alaska Natives

Literacy, Health Communication and Diabetes Disparities
Dean Schillinger, MD

Dr. Kelly Acton:
Good afternoon! Could we get everyone to take their seats and get started. My name is Kelly Acton, I am the Director of the Division of Diabetes for Indian Health Service, and I see a lot of familiar faces out here, which I am really glad you guys decided to come to this.

Last year, I was invited to give a talk up in Missoula, Montana, my old home, and I said, of course I will go. The person who spoke before me was Dr. Dean Schillinger. As I sat there listening I was remembering that in IHS we used to do a lot of health literacy work. You all remember? In the Diabetes Division we used talk about low literacy, we used to go out and do those different tests etcetera, etcetera. We've kind of gotten away from that. I sat there listening and realized there is a whole new generation of health literacy and innumeracy knowledge that we -- I don't think are using a whole lot in our system. Dr. Schillinger was up there talking about this stuff. He is the Director of the UC San Francisco Center for Vulnerable Populations at San Francisco General Hospital. He was talking about some of the work that they are doing. I was like, we've got to get this guy to come talk.

So I called up Ann Bullock and said, we've got to invite him to the next Advances, and here he is. So I am going to -- I have the honor of introducing Dr. Schillinger to you, not only is he very well respected in the Diabetes world, but he is also just a very nice guy. So I just had lunch with him and asked him if he'd let us do a field trip out there to see some of the work that they are doing and maybe try to incorporate some of this into what we are doing now. He is also the Chief of the California Diabetes Program in his spare time. So without further ado, Dr. Schillinger.

Dr. Dean Schillinger:
Thank you, Kelly! Really the way they got me out to Missoula, Montana was they said, well, Kelly Acton is going to be there, totally true!

Well, it's an honor to be speaking to you today. I will start off with two caveats. I am going to be reviewing what's been studied about the relationship between literacy and diabetes. So I will be reviewing a lot of research. But the caveats are that I am a Primary Care Physician. I am a General Internist and almost all of the research that I am going to share with you has to do with doctors and doctors speaking with patients.

I have not studied nurses or pharmacists or health educators. I think those of who are nurses, pharmacists, and health educators are in a much better position to study your selves than I am.

It's very hard to get into the room to study communication. So you have to be from the tribe so to speak to be allowed in. So that's caveat number one.
 I will say though probably some of the findings that relate to health communication in a doctor's and patient's office encounter do have relevance to other health professionals' communication.
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We have all received health professions training and learned second languages. So almost invariably it's going to be relevant to your work if you are a clinician of any ilk.

The second is none of the research that I have done has been done in the Indian Health Service or with American Indians. I will leave it up to you to decide whether or not the findings we have and some of the implications are generalizable to the work you do. I suspect some of it will be, others of it may not be.

So I am going to start out by talking about my home town which is San Francisco, to point out how big a problem we are talking about when we talk about disparities and diabetes. This could be done for any county in the United States. The fact that it's in San Francisco which is arguably one of the wealthier counties in the nation is particularly striking and I think San Francisco is in many ways representative of where we are going in this country, because it is tremendously ethnically diverse.

So, let me orient you to this slide. This is a map that portrays the rate of hospitalizations for 100,000 people for uncontrolled diabetes, amputation, dialysis, Ketoacidosis. This is not heart attack for someone with diabetes; these are things that clearly are metabolic derangements or acute complications of diabetes. These are adjusted for the age of the people living in these neighborhoods. So let me start out by showing you the rate. Let me pick the Inner Richmond. How many of you have been to San Francisco? Wow! You guys are well-heeled.

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Alright, this is north of Golden Gate Park. It's not the wealthiest neighborhood in San Francisco, it's where the people who moved to Chinatown. This is the real Chinatown, this is where their kids then bought a house or rented an apartment. So this is sort of the second generation. This is the Russian, Jewish, Chinese neighborhood. You can get any kind of noodle, you just can't get a piece of bread, but you can get any kind of noodle.

So, the neighborhood I live in is Inner Richmond -- our rate of hospitalizations for uncontrolled diabetes there are 172 per 100,000. If you look at the neighborhood where San Francisco General Hospital is, the public hospital, it's Potrero Hill here and it starts [Inaudible] here. The rates there are 419 and 1,176. So essentially a tenfold difference between what would be considered a middle-class neighborhood and a more or low income neighborhood in the southeast corner of San Francisco.

If you compare the Marina District; how many of you have been to the Marina District? That's right near Fisherman's Wharf. It is a well-heeled upper class neighborhood. There is a 12-fold difference in the rate of hospitalizations for diabetes between Bayview-Hunters Point and the Marina District. That's a tremendous public health disparity.

And it reflects disparities in the incidents of diabetes, how many people have it and the control of diabetes, access and quality to care. So in fact, this color coded map, it's so dark you can't even see the number in that southeast corner. It's 1,176 compared to 95 in the Marina District.

So what's going on? That's not as we heard about this morning, which was a fabulous talk. This is not genetic differences between people living in Inner Richmond and Bayview-Hunters

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Point. What is it? As a teacher of residents in our primary care program the residents always want to do two things, they want to have a differential diagnosis of the problem. So if someone has a cough, they have got 13 things in their head about what could that cough be from the common-cold to tuberculosis, sarcoidosis, you name it; all the osises.

So, they want to have a differential diagnosis and the second thing they want is a mnemonic, a little trick to remember that 13 causes of cough. So we tried in our work to teach social medicine. We've tried to do this here, which is to create a social differential diagnosis. When you are with a patient and things aren't going as they should, maybe they have got diabetes and their trajectory is towards dialysis, or you name the problem. It's just not going well.

It's possible that you have the wrong diagnosis. You need to run through a differential diagnosis, but it's also possible that have not assessed for some of the social vulnerabilities that are common amongst the patients we take care of particularly in places like San Francisco General Hospital.

So here is the mnemonic vulnerabilities and you can look across each letter to see where your patients line up. The point here is that it's an extensive list. All of these individually have been shown to be associated with health outcomes in one disease state or another. They are all appropriate targets for clinical and public health intervention.

The sad thing is that many of these co-exist simultaneously in individuals, in neighborhoods and communities. So if I were to -- I am going to go back. This was Rates of Uncontrolled Diabetes. If I were to map literacy rates in San Francisco, it's going to be the same map. If I were to map violence, if I were to map homelessness. You get the picture. The clustering of vulnerabilities is a significant problem and much of the research that's gone on in Clinical Medicine has tried to just look at the isolated effect of one of these and that's what I am going to do today and it's clearly problematic.

I am going to talk about let's see where does it show up? The third letter, literacy, and maybe language. But we must -- of course, acknowledge that this is difficult to disentangle from race and ethnicity and culture and access and insurance and eyes and ears. If somebody is hard of hearing, they probably are having communication difficulties, so it's artificial. A lot of research is artificial, but I think it will give us a window into the problem. So I am going to review some statistics and definitions regarding literacy and health literacy in the United States.

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Describe some research that shows the associations between health literacy and health outcomes with diabetes as exemplar. And I recently learned at lunch about some new research done in IHS settings that maybe we'll have a call out and here what you all are finding.

I want to share some of the work we've been doing around health communication interventions that might have some relevance, and then I am not going to talk about pediatric care actually.

So this is how the Institute of Medicine has defined health literacy and I can tell you that you could get people who study this, who work on this in clinics in a room together for weeks and

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they'd be throwing tomatoes at each other trying to get agreement on this definition. So for whatever's worth the Institution of Medicine in their 2004 report defined Health Literacy as the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make and I added this bracket here, to make informed health decisions.

So one of the problems with this definition obviously is that it assumes that it's a fixed capacity, that it's not mutable, changeable; it also tends to inappropriately focus the problem on the individual rather than the health system. That if you think about health literacy as a balance between the demands that we place on patients and the training and capacity that they and their families have to deal with those demands, you begin to think about health literacy in a slightly different way. So I think just remember it's a two-sided coin, we have a role in determining whether our patients have high or low health literacy just as much as they do and the systems in which we work as well and I think I will show you some of those, some data to reinforce them.

Most of us in the field think about health literacy as having between three and five domains. Oral Health Literacy, which relates to speaking and listening. We've all had the experience of trying to illicit a history from a patient and as you well know there is tremendous variation and how capable our patients are in articulating the problem that they are having in ways that we understand. So there is some important skill-sets around oral communication that many of our patients lack in ways that we understand. And the talk this morning I think was very compelling around how early childhood development also shapes exposure to words and can shape vocabulary in very powerful ways that might have implications for health down the road.

The second broad domain is obviously Written Literacy which has to do with reading and writing. And the fifth, or third or fifth depending on how you want to count, is Numerical Literacy or so-called Numeracy or Quantitative Literacy. And as I learned at lunch from Angela, Numeracy maybe particularly important in determining diabetes outcomes in the American Indian population. As I said before, Health Literacy is probably best thought of as a balance between the capacity of the preparedness of the patient and family and the demand that we place on patients with respect to the disease and that mismatch therein.

So the National Assessment of Health Literacy was a nationwide assessment of the literacy skills of residents of the United States. It measured literacy skills in a number of domains, but had a particularly deep look into health domains. And the way it worked is the US Department of Education, this was funded in the pre-Bush era but actually took place during the Bush administration surprisingly, went into the homes of a random sample of residents and identified the highest self-rated reader in the family.

So if that was grandpa, then grandpa we're going to assess, if it's uncle, that's who we're going to assess, if it's the high school kid, that's who we're going to assess. So it's in many ways a best case estimate, because they ask for the best reader in the family. They subjected this poor soul to a battery of literacy assessments including things that I had mentioned that were health-related. And the system that they develop to code the categories is like the 9/11 airplane safety. We were on Orange in Albuquerque when I landed, we're always on Orange.

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So red, orange, yellow, and green. Red or below basic, 50% of people in this category could correctly circle a date on a doctor's appointment slip. Orange or basic, 50% of respondents could correctly give two reasons a person with no symptoms should get tested for cancer after having read a clearly written pamphlet about prostate cancer screening that was written about the fifth grade level. So to be able to be answer some multiple choice questions around, if you don't have symptoms, urinary symptoms should you still get tested for prostate cancer, yes or no?

Yellow or intermediate, 50% of respondents could correctly determine what time to take a prescription medicine based on a typical pill bottle label. And green or proficient was the ability to calculate an employee's share of health insurance cost using a table. I didn't really understand that until I have to decide about a year ago, so whether or not I should take my daughter to the emergency room for what might be a sprained ankle or a broken ankle and I looked up on the web and you sort of look at your employee, an employee of the University of California the Sheriff cost; if I bring her to the emergency room it's $75. I will just wrap an ace-bandage around it. So that was proficient, maybe it was very health ill-literate -- she turned out to be fine so it was the right choice. But that's what that is, right? It's looking at an insurance document and figuring out what you're going to have to pay if you do a certain action.

This is how health literacy skills are distributed in the United States. The average Medicare recipient is at the cusp between basic and intermediate skills. Only 12% of us are proficient, and it's interesting that health plan material is really proficient, health literacy demands, 14% are at the below basic, the Hispanic residents are in the basic level. Clearly again returning to this morning's talk, a consequence of exposure to either limited educational attainment in the home country or poor quality early education in the United States. So, a little over half have intermediate health literacy skills.

What do we know about the relationship between literacy and health particularly in diabetes? This has been best studied in older people where it has been shown to clearly be related independently to where self-rated access, lower self-rated health, very strong relationship to self-rated health, a tripling of the proportion of people who report that their health is fair or poor. Higher rates of particularly the cardiometabolic cluster of diabetes, obesity, and hypertension, higher adjusted mortality; and in safety-net settings with diabetes, it has been shown to be associated with a number of diabetes outcomes that I will share with you.

This is work by a colleague of mine Rebecca Sudory who studied a community dwelling cohort of older folks, the average age I believe here was 73 and found a strong association between limited literacy and higher prevalence of hypertension, diabetes and obesity even after adjusting for everything you can think of. Now, this again is probably an underestimate because if you lived, if you made it to live to 73, you're a long-term survivor. The folks who had limited literacy skills and had heart disease at the age of – what was the mean age of dialysis, it was 58, I think that's right. A lot of folks didn't make it to be in this cohort to assess whether or not literacy was associated with health. So I believe this is an underestimate.

Clearly, having limited literacy creates an impediment to effective teaching in the clinical encounter. These are data that were collected at Grady Hospital in Atlanta among patients with Type II diabetes, all of whom had primary care physicians and have received diabetes

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education. And despite that, those with limited literacy came away with much lower understanding of the need to know what the symptoms of low blood sugar are, that's a survival skill and knowledge with respect to the need to do, what is the correct action for hyperglycemic symptoms which is eat something with a lot of energy pretty quickly. So a clear gradient in knowledge for diabetes by literacy level. Now, many of us believe that knowledge does not equal outcomes. It's not that if you know everything to know about diabetes, that your hemoglobin A1c, blood pressure and cholesterols can be phenomenal and that's almost certainly true.

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However, there probably is a basic set of information that everybody with diabetes or heart failure or whatever the chronic disease is needs to know in order to function safely and this is a good example of that. I'm going to return to safety in a minute. We study this in a very ethnically diverse public hospital setting in diabetes, specifically asking the question, whether or not literacy skills were linked to hemoglobin A1c. This work was exploring the independent relationship of literacy and hemoglobin A1c, after adjusting for educational attainment, race and ethnicity, medications people run, everything you can think

So even in that adjusted model, the odds of having good glycemic control here on the left side were about half that among those with inadequate literacy skills compared to adequate literacy skills. Conversely, those with inadequate literacy skills had double the odds of having very poor glycemic control, this was hemoglobin A1c greater than 9.5%. Clearly showing that there's something going on related to quality of care and literacy and health literacy that needs intervention.

So even in that adjusted model, the odds of having good glycemic control here on the left side were about half that among those with inadequate literacy skills compared to adequat.
This was not just a phenomenon related to the blood test, right. You could always say, well, that was one blood test. Diabetes is a lifelong illness. What do you know? Well, we found that same relationship of two odds, adjusted odds of having retinopathy, nephropathy, amputation -- the two number just keeps popping up. Even after adjusting for all those things, age, education, etcetera.

So that hemoglobin A1c slice in time appears to reflect a much longer exposure to poor glycemic control and the microvascular small blood vessel complications of diabetes. Obviously, the biggest one being kidney disease as we talked about this morning. Now, I'm going to again point out that this relationship, this rule of 2s is probably an underestimate in this population, because in order to get enrolled in a study that assesses literacy you need to be able to see really well, because it's not fair to assess someone's literacy level if they have retinopathy that's pretty bad or if they forgot their glasses as many patients with low literacy often do.

So we excluded anybody who had a diagnosed retinopathy that impaired vision, anybody who forgot their glasses, etcetera, and that was a lot of people. So anybody who had who had symptomatic retinopathy, presumably many of those folks have limited literacy. We are not in this cohort. So, this is probably an underestimate again.

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Now, I'll just say, I've been studying this problem for about 12 years and I've really tried to make the case that we need to -- as was made this morning, we need to invest in early education and I will share with you some comments that were pitched to me at a grand rounds that I gave at my home institution, UCSF, by someone who I will not name, who said, you've made a really strong case for how this is really important in the safety-net, but what about for "real people"?

The idea was, if you really want to move policy, you can't only be talking about disenfranchised people, because issues that face the disenfranchised don't move the political needle very far. That was a very cynical question, but it did motivate me to try to move a little bit beyond my clinics where we do truly serve the most marginalized members of our society to a middle class context, a health system that in many ways is much alike your health system than a public hospital system is and that's Kaiser.

These are data from Northern California, Kaiser. And the first question we actually want to know was how common is limited health literacy among people with diabetes? At Kaiser, that's not shown here on this slide and it was about 40% of people at Kaiser had limited health literacy skills. So, a couple of points. One is I showed you earlier that literacy is associated with diabetes. So, while the general population has pretty high rates of limited literacy skills among those with diabetes, because diabetes just proportionally affects the poor, limited literacy skills are much more common.

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So 40% in a system like Kaiser. We were interested in studying whether or not literacy here measured indirectly by asking patients to report problems, learning about their medical condition because of reading issues, needing help reading Kaiser forms, reporting not being confident completing Kaiser medical forms, were strongly associated with several hypoglycemia.

What we ask people here was in the prior year, did you ever have an episode of low blood sugar in which you lost consciousness or required you to get help from another person? Now, the first thing to note here is about 9 or 10% of the Kaiser population had had one or more episodes of severe hypoglycemia, that's just shocking! The studies, the DCCT and the UKPDS, all the things that drive our practice in primary care and endocrinology diabetes care, report rates of severe hypoglycemia, 1% per year, really low rates, right? We've just translated all of those findings into community, without necessarily having the infrastructure that these well-designed, well-funded randomized control trials have.

So in a community-based setting, a fairly well-resourced setting with patients who are fairly well-resourced as well, about 9 or 10% of them are having one or more severe hypoglycemic episodes. This is Type II diabetes. Those with limited literacy skills, the 40% or so, had, again, Rule of 2, double the odds of having had one or more several hypoglycemic events.

So, extending the work to suggest that literacy is not only associated with incident diabetes, how many people have it, and quality of care, what's your hemoglobin A1c, but safety. Are you dropping out with Hypoglycemia? And then to put the nail in the proverbial coffin, acknowledging the life course trajectory and the importance of exposure to early development, nonetheless we see this playing out in that elderly cohort wherein those with limited literacy

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skills where the Rule of 2s, twice as likely to die over a five-year period of time than those with adequate literacy skills, in a community dwelling sample of older patients.

So, why is this happening? Why is literacy associated with diabetes outcomes? I think we had a great, eloquent discussion of the role of early development. When you think about early development and literacy acquisition, they are tightly-linked. So, I'm going to remind us of that as we go through these hypotheses.

The first reason may be, well, this is a so-called confounder. You're picking up limited literacy in a 50-year-old is a reflection of something that happened when they were two and three during that critical period from neurons to neighborhoods. Now, whether that's a confounder or mediation, we'll talk about in a minute, I don't know, but insofar as I've talked about in the beginning of these vulnerabilities tend to cluster together. It's possible that even though we try to statistically adjust for these confounders, right, we adjust for income and education, that does not really capture a person's lifelong exposure to wealth or deprivation. So, it's possible that this is a confounder.

The second possible link is that there is something going on at the neighborhood level, as I showed you in that map of San Francisco in the beginning, wherein limited literacy is associated with health mediators, differential exposures in the neighborhood, in your family that then is associated with illness.

The third, I think, quite interesting hypothesis, and you'll have to bear with me a little bit, is that people who are on a worse trajectory, let's take the person with hemoglobin A1c of 9 and a creatinine of 1.8 or something, they are on the road to complications with diabetes. Then we waltz in eight years later and we measured their literacy level. And they already had some evidence of end-organ damage, the kidneys aren't working so well, maybe the small blood vessels in the brain have been affected, and that higher cognition in subtle ways has been affected. We see this with our older patients in particular. They don't have dementia, but their executive functioning appears somewhat impaired. And then we stick at test in front of them, that asked them to comprehend words, answer multiple-choice questions and we call that Literacy and they score poorly. And then they do worse in their health. But the literacy assessment was just an innocent bystander of a process that was going on anyway.

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Now that's very important because it does speak to where we may want to intervene in the problem of vulnerability and worse health. But it also does have, even if this hypothesis reverse causation or cycle is true, it does mean that we need to be aware of the limited literacy skills, even if we are measuring it eight years into it, right.

If we were having the same kinds of communication with that person as we would in someone who might not have subtle cognitive impairment, we have missed the boat.

The last mechanism which I think is probably the predominant mechanism ,where in limited literacy affects quality of care, has to do with us. And it's the fact that we may – it maybe that limited literacy is associated with health trajectory but we can either make it worse or better depending on how we operate. That's the so called Effect Modification. That the quality of care that we provide may vary depending on a patient's literacy level. And I'm going to make the

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case for this, because I think it's a motivation for us to change how we do business. And I think a lot of it is about communication.

So here is a guy -- sounds like you guys have had this conversation in your -- we know it's been well studied that we leave the office encounter with often a very different impression of what was said and what was communicated than do our patients. This is a pretty visual example of that. I think this is true for anyone, anyone who is seeing any kind of professional. If I see the car mechanic, 50% chance I understand what he is saying. If I go to my health IT guy because my computer is not working about at 20% chance I'm going to understand what he is saying. I'm going to nod my head. I'm going to do whatever he tells me to do as best as I can. But we're probably not seeing eye-to-eye.

So could poor communication be a mechanism to explain this consistent relationship between limited literacy and indicators of quality of care? I think there are lots of reason why it maybe. One is that we really place high self-management demands on our patients with diabetes. It didn't use to be this way, right? I mean in the 70s, I think it was like maybe a urine dipstick, right, because of your ketoacidotic that we want to know.

Now it's like we want your hemoglobin A1c 6.8 all the time. You got to basically run an ICU out of your kitchen. The demand side, the demand side has really increased and it's increasing. I am not saying this is good or bad, I am just – it is what it is, right? Andy Narva have talked this morning about our patients need to come in and ask what their estimate -- talk about their estimated GFR and their amount of protein that they are spilling in the urine, these are very high self-management demands.

There is an increasing reliance on technology, whether that's personal health records, patient portals, funky glucometers, mobile smart phones. We want our patients to use these things. And there is a large mismatch in the training that we as health professionals have and those of our populations we serve. By that I mean we talk about diabetes in very different ways as a consequence of our training. And we have not unlearned how to talk about diabetes. And that gap some people refer to as the health literacy gap.

Okay, so some of the research and insights that I'm going to talk about here rely on a very simple and simplified, overly-simplistic framework for communication in chronic disease care like diabetes care. But this, the same could be shown for depression care, for heart failure care. Essentially we as clinicians have two jobs. If you want to look operationally what's going on, we have to elicit, that's over here. How you're doing? How are those blood sugars? How is the mood or how is the walking? We have to draw out some information from our patient about things like their disease state. Are short of breath after two blocks, after five blocks, how depressed are you?

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We have to elicit barriers. In my setting it's often, are you able to pay for your medications, right? You mentioned food and security this morning. In the last month, have you had difficulty putting two or three solid meals on the table? So that needs to happen. We also need to explain, a lot of people who think about communication really think it's – oh yes, the explanation is safe, yes, the explanation is part of it, but it says as important as elicitation.

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So explanation is here is the diagnosis, it's chronic kidney disease, it's diabetes. Not easy to do and here is the treatment plan. I want you to take these medicines. I want you to check your sugar this way. And really what we are trying to do is to achieve some degree of concordance or agreement in these four domains of diseased state. How you're doing barriers. What problems are you having, diagnosis and treatment plan.

I am remembering that slide before of the guy with a big glass of whiskey, whatever that is, knowing that we don't often achieve concordance. But the thinking is, if we can achieve concordance and do it in the context of a therapeutic alliance or a trusting relationship, then we have a prayer of improving health outcomes.

So how does limited literacy affect this communication? In the 90s I think when you had the Doak's come and talk to IHS about Health Literacy, it really was thought of as a problem, reading the brochures, and the pill bottles. And if we could fix the brochures, we would be in a better place and not say, we shouldn't fix the brochure, as we should, but it's pretty clear as I mentioned in my introductory comments about the five domains of health literacy that this spans communication in many domains, verbal communication particularly, and at least in my settings still most of the communication I do as a primary care doctor, it's verbal.

Sometimes I give a brochure, very rarely do we have a video or a website, it's mostly I'm going to talk to you for 15 minutes; maybe you'll get a couple of words in edgewise. And you must remember everything I said, understand it and do it. That's not great, that's not a great system. And if you have a somewhat a restricted vocabulary, particularly around technical information, that's going to impede self-care, and we've clearly shown that to be the case.

Impair share decision making, the speed of dialogues, what I mean by that is health professionals talk very quickly. The extent of jargon we use, I'm going to come back to that. The lack of interactivity, the lack of two-way speak. It's really predominantly unidirectional, really impair communications for everybody but particularly so for those with limited literacy, not only disadvantaged in terms of understanding but much less likely to challenge the health professional to say, could you go over that again, because I really wasn't sure, right. How many times has that actually happened to you in a visit? Pretty rarely and it tends to be from people for whom the social distance is more narrow, between you and they. Clearly affects medication communication for the issues of Numeracy as I talked about before, jeopardizing in patient safety.

To give you a flavor of how bad the problem is in terms of verbal communication. You guys probably do – you do waiting room, patient satisfaction surveys like everybody does? Alright. And it's always 90%, love the doctor. It's never 90%, never 80%, it's never 70%, essentially whenever you survey patients in the waiting rooms about their doctor, they love the doctor. I mean why would they be coming to the doctor. Why would they be in the waiting room for the 11th time in this year if they didn't love the doctor?

So when you start seeing dissatisfaction or negative reports of primary care physicians that exceed 10 or 20%, that start getting into 25, 30, 40%, that's a really important red flag. And we see here, these are data of patients with diabetes, reporting on communication with their primary care physicians at San Francisco General Hospital. Good doctors, committed to serving the under-served, saying they often always don't understand the words the doctors use.

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They often always these doctors give them test results without explanations, often or always confused about their care. And this is interesting when we think about elicitation, that their doctor only never or rarely understands the problems they might have in caring out the recommended treatment plan. So we'll make a treatment recommendation and move on without ever assessing that insulin regimen we start, how is that going for you?

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So I became intrigued by these really high rates of dissatisfaction and wanted to get as I mentioned before into the black box of what's going on in these primary care visits. I just want to share some kind of fun stuff with you. Kelly knows I talked about this in Missoula that this is the kind of stuff that you would have thought people have studied, that somebody somewhere pressed 'record' in a doctor patient encounter and assessed jargon. It hadn't been done. The kinds of research that have been done had been going to the local mall, opening up a dictionary, pointing to the word Hemoglobin A1c and lo and behold, 99% of mall goers do not know the word Hemoglobin A1c. The sky is falling, and obviously the critique is, well, why should the average - Joe know what Hemoglobin A1c is because when I talk about it in the visit with my patient with diabetes, that's when it's important and they understand it because I have been talking about it for 20 years.

So we wanted to measure the use of jargon in typical primary car with doctors I think that are probably similar to the kinds of doctors who choose to work in your setting, well-meaning, well-intended caring people who've probably heard a lecture or two on communication, who understand the importance of connecting with their patients for diabetes. And we counted up the number of terms that one could consider to be jargon and we only dinged the doctor, if you will, we only counted it if the doctor just put out the word and didn't clarify it. So if the doctor said, I want you to get a Glucometer, that's the machine that th nurse gives you to check your blood sugar, we didn't count it because the doctor explained it. But, if the doctor said I want you to get a new battery for your Glucometer, we counted it.

The first thing we noticed was there was a fairly wide range of jargon terms that were being used. I should tell you, there is no dictionary of jargon, you can't decide if a word is jargon or not based on the word itself. You really have to assess the receiver's understanding of the word. But I think we could arguably say that there were words that were clearly medical jargon like the fourth bullet Microvascular Complication, I used that word earlier today; Microvascular Complication. You can only find that in a medical dictionary.

On the other hand there were words like if you look from the bottom, let's see the third bullet, your weight is stable. We heard this a lot. So wow! Your weight has been pretty stable, your blood sugar has been pretty stable. So what does that mean? What is stable for clinicians is no change over time, right? That's a very clear scientific, right? We measure things, we follow them, we assess stability, increases, decreases, but what is that to most people, stable?

It's where the horse stands in. Okay, so your weight is stable, right? Go down the bullet points to wide range, those blood sugars. That's a wide range of -- on that Glucometer, that's a wide range of blood sugars, right? That's a lot of ups and down. What is the range? Where they were, the buffalo roam or the horse in the stable roams. So that's lay jargon, that has dual meaning. That's a word that has dual meaning, a scientific meaning and a human meaning.

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Alright, so we heard a lot of that. Let me just share with you some things we were interested in. One was where are these unclarified jargon terms presenting themselves in the visit and they were presenting themselves at exactly the wrong time when we were trying to teach our patients, when we were providing recommendations, when we were providing health education. The JPMs (Jargon Per Minute) was 0.4. That was sorry, the UJPM, the Unclarified Jargon Per Minute. We didn't count drug names by the way, we just felt if someone says Benazepril, yeah, whatever, we're just not going to ding them. But if you counted meds and if you counted clarified, I am sure the JPMs would be a lot higher.

So we're using these terms to teach our patients presumably because that's how we learned to talk about diabetes. Microvascular Complications on down, and we have not unlearned that nor have we really learned I should say how to talk about diabetes. So seasoned, I will say, the more seasoned clinicians in this cohort had lower JPMs than the more junior clinicians in the cohort, suggesting that seasoned clinicians have learned from their patients how to talk about diabetes, they have unlearned the Glucometer and what have you.

(00:45:18)
So let me give you a flavor and I am going to use the word Dialysis, because that's what we were talking about this morning with Andrew Narva, and since it's such a big problem. I am just giving you one example of how we understood this jargon stuff.

This was a quote from a colleague of mine who is an absolutely wonderful physician, who was trying to give positive feedback to her patient who had a hemoglobin A1c of like 7.2, very good, and a blood pressure, that was great, and she was trying to give her positive feedback by saying, you know what the number one cause for people in this country being on dialysis is diabetes, and you are not going to need to be on dialysis.

So what did that woman come away from with that nicely intended comment? So we called that woman back after a couple of weeks and we called men and women like her from this cohort. So every jargon term we called people up and we asked the indexed patient and patients like her who were in that cohort as well and we gave them the whole excerpt of the whole paragraph and we asked them to, how well do you understand this word, what in your own words does it mean, etcetera, etcetera, and I just want to give you a flavor not to be funny but to be real about what people come away with after we say things like this.

Would you please tell me in your own words what Dialysis means? Check something every day. Well, that's probably diurnal or daily, it's pretty close, but it's not dialysis. What is that about your toes? A one means no understanding by the way. It means that your diabetes is going worse that you have to exercise to make diabetes. You've got to get on the machine to pump, redo blood, to come up to par. That's pretty good. Andrew Narva, you want to hire somebody? We've got somebody for you here.

But, the point here is tremendous variation in how much people understand medical terminology, and I will tell you the best, this is the percent of comprehension, anybody who scored a 3 or 4. It didn't matter how we framed it, it didn't matter if it was from the patient's own visit, if it was the doctor clarifying the word, if it was a word like stable or range or a word like Glucometer, you never got to 30-40% comprehension. It really suggests that jargon is not really empowering. I must admit that sometimes I've tried to teach people medical concepts as

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a means to empower them, and I am just not convinced that it's helpful and I am pretty convinced that it's not. I think that when I thought about this clarification, why would not -- why wouldn't clarification increase comprehension rates, and I could think of two analogies, one was it's like Charlie Brown. The Charlie Brown is in school and he is like on his desk and the teacher goes wow, wow, wow… maybe that's what we sometimes sound like.

The second is going back to my IT guy when I have a problem with my computer and I sort of mopishly go into his office and again say like, "I can't log on". And then he starts going off on like the SQL Server and all this stuff, and I am just like, "Fix the computer!" It's not very empowering for me for him to be talking about the SQL Server when I just can't even log on.

So I think there is something there, and if you throw in the issue of power and social distance and unwillingness to challenge and ask, I think it's pretty clear that we need to stop using jargon and use I like as Terry Davis used, use living room language, whatever that means because people talk about different things in their living rooms. But I think understanding what goes on in living room language, I will just take small digression because it's interesting. This has actually been studied in a randomized trial in the United Kingdom where they took women who were presenting to an urgent care clinic with pelvic symptoms of some kind incontinence, dysuria, painful intercourse, and the doctors were randomized to either use words like incontinence, urinary tract infection, pelvis in their explanations or living room language like things like your bootie down there, and incredible.

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The women who are randomized to the doctors who used living room language had a more rapid improvement in their urinary and pelvic symptoms over the subsequent week in an urgent care clinic. The first, I think, well done study of whether use of scientific terminology is empowering or not. So this problem I think has the potential for getting worse.

These are data again from Kaiser who has invested I have learned $5 billion in their electronic health record and patient portal; that's kind of mind-numbing. My colleague Urmimala Sarkar is interested in health IT and disparities, and health IT has been thrown up as -- it's going to solve everything where finally we have reached Utopia. The question is, if you have limited literacy skills and you are at Kaiser, and you are much more likely to have a worse hemoglobin A1c blood and you are the ones who need the electronic health record, right, the patient portal, how is it going for you? They have now had it for about six years. The first thing she found was the proportion of people with limited literacy skills in the light gray here was lower among registered users, that means did you ever register, did you ever get a log-on password, anything, and it's a marker for do you even have computer access, right, because that's one of the first things, do you have computer access. So clearly a divide in access to computers, that's that left bar that registered users. Everything else was only among those who registered. So only among those with computers.

As you can see, a continuing disparity in people's ability once they have access to actually use it and navigate it, for things like making an appointment, getting refills, viewing your labs, emailing your doctor, this is the currency of the next decade. This is how we are going to be doing business, and unless we change the interface in ways that makes sense to our patients who have the greatest needs, there is potential for this divide, the digital divide that have

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health implications and consequences particularly in diabetes, those diseases that require ongoing self-management.

So, what can be done? I mean how many of you have heard about or use, I'll give you either one, the Teach-Back Method? One, two, three, four, okay good, five; may be one-sixth. You may be doing it, but call it something else. But there is one thing I want you to take-away from this talk, use the Teach-Back Method. The Teach-Back Method is a very efficient and effective simple communication technique to use in the 15-minute visit and it essentially is a means to assess the success of your communication. I will give you an example. You start new medication or you give a new diagnosis, and you say, Mr. so and so, I want to make sure I did a good job explained to you about chronic kidney disease or about the new medications. Can you just teach back to me what you are going to do when you go home? So I make sure, I did a good job or I can clarify if I haven't.

 An explicit request of the patient to teach-back to you what you have decided is the key concept or change that you have done in that visit. Use it early, use it often, it really allows you to assess, recall, it is not -- so do you understand, are we on the same page here, because you get right, the kiss of death, right. Yes doctor, it's an explicit elicitation of recall and comprehension, and it's wonderful because first of all you will see that you pretty much stink as an educator. Right about four times out of ten, what you thought you did a great job of was remembered. Second, when you listen to how people teach-back to what you have taught them, you will be able to use their living room language. How they conceptualize diabetes, or whatever the issue is. So it really opens up a dialogue. It is not in my experience Pandora's Box, in my setting you have 20 minutes with a patient. That's what you have, it's 20 minutes. It's what you do with the 20 minutes, and so the Teach-Back Method is effective. We found in another study in which we audio-taped my colleagues, that only 12% of new concepts were links to a teach-back opportunity. We are not doing this, and at least primary care physicians are not doing it.

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When we did it, patients got it wrong about half the time, meaning, we didn't succeed in the first round, visits that use the teach-back where the communication loop were not longer, they were essentially the same. But those visits in which the Teach-Back Method was used those patients had hemoglobin A1cs, that were much more likely to be in good control. It's not an experiment; I am just saying that it appears to be associated with patients having greater role in their self care.

Because I am running out of time, I am going to not talk about health education brochures, because you know about this a lot. But I am going to talk about use of technology in a different way, and I will close there. So I shared with you the concerns I had around the patient portal, and my concern there is that the end-user most likely to need it was never really included in the development of the tool. We tried to do something a little bit different in the Community Health Network, which is our Public Health System in San Francisco by using a pretty simple technology, and I just want to share with you those results and I'll close.

This technology, we called it Automated Telephone Diabetes Self-Management Support, is not a replacement for care, is not a replacement for communication with the healthcare professional, it's not a replacement for our therapeutic alliance, it's an adjunct. The automated

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system makes weekly calls to patients with diabetes in their language, and in our case it was English, Spanish and Chinese, to provide weekly monitoring and basic health education in the form of narratives. Patients respond with the touch-tone, very low tech, and if they respond beyond a certain threshold, if they say that their blood sugar is 40 or they have got a foot ulcer or that they are still smoking, or that they are five colas a day, or whatever you decide to set, a care manager or health coach gets alerted to that response and can call the patient back promptly the next day, two days later, whatever, to engage them in collaborative action planning. So it's a weekly ongoing program to support patients in their self-management to write a basic level of surveillance in education.

Let me share with you -- or I should tell you, we studied this in the randomized trial, compared to usual care and compared to group medical visits. Many of us run group medical visits, and our firm believers in the benefits of group medical visits, but one of the question is, how do group medical visits compare to other ways of delivering self-management support?

Let me share with you some of the results. These numbers quantify the reach of the program, it answers the question, if you build it, will they come, if you have a group visit, will people come and make behavioral action plans. If you have an automated system, will people pick up the phone, use it, and engage with a nurse or health coach and make action plans; that's all this is measuring, higher numbers are better reach. We found that the Automated Phone System had nearly a five-fold greater reach than group medical visit. This is not to say that if you came to a group visit you didn't do great, it's just if you take all comers, and you look at who's coming and who's using and who's benefiting, the simple technology was superior.

The exciting part to us was that those with communication barriers were much more likely to have greater reach with this simple technology than those who didn't have communication barriers, and conversely those with communication barriers in the group visits which are much more similar to usual clinical communication perhaps, were least likely sort of nearing typical patterns of engagement.

We also found -- I am going to move to this slide that the Automated Phone System, which is the middle set of bars here, if you compared baseline in one year, folks in the Automated Phone System were much more likely than those in usual care or group medical visits to have significant improvements in their quality of life, no matter how you measured it.

If you have diabetes, what's probably more important to you than your blood pressure and your hemoglobin A1c is, how many days in the last month did you get out of bed? Were you able to get out of bed? How many days in the last month did diabetes interfere with your activities of daily living? Now as I say the hemoglobin A1c isn't important, it is 10-15 years down the line, what's important today is, did you get out of bed and did diabetes interfere with you.

So, we are now scaling up this Automated System, the local health plan because you can do research but really the questions that we are making an impact, right, this is two wolves looking -- they are all howling at the moon and one guy says the other like, "Okay, we are howling at the moon, but are we making an impact?"

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(01:00:04)
So, we're doing this now with the health plan, a Medicaid Health Plan to see if this thing we studied in a research setting can actually work in the real world.

So, let me wrap up because the time is running short by saying that, we're not really sure how limited literacy affects diabetes outcomes, but I am pretty sure that part of it has to do with us and how we communicate and the systems in which we are working that either foster or impede effective communication. Absolutely clear that we need to improve literacy levels, I think the ways to do that and the ways we heard about this morning, which is to improve the experience in utero and in the first few years. And that by doing so, we could achieve some important public health objectives and reduce disparities.

The communication characteristics of the healthcare system contribute to suboptimal healthcare, I think you guys are perfectly positioned to be front-end innovators around reengineering the system And at that reengineering, I think we begun to see some movements, some small studies that suggest that use of appropriate technology and other reengineering schemes can improve the reach of healthcare, because that's an important thing, who's coming, who's engaging, improve quality and promote safety.

I'll stop there, it's my daughter, who I miss, and open up for a few minutes for questions, Kelly, is that -- sorry, okay. Thank you.

Total Duration: 63 Minutes.

[End of transcript.]

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