Hello and welcome to the April 2016 Harvard Medical Labcast. This podcast is brought to you by Harvard Medical School’s Office of Communications in Boston. I’m Stephanie Dutchen.

And I’m Jake Miller.

In this episode, Jake tells us about how understanding the context of an outbreak like Ebola, including personal, political, historical and environmental factors, in addition to the biomedical factors, is crucial to preventing future outbreaks.

And in today’s conversation, Stephanie speaks with HMS Associate Professor of Medicine Joseph Betancourt, who directs the Disparities Solutions Center at Massachusetts General Hospital. His work here at MGH and with other U.S.-based organizations mirrors a lot of what we saw in the Ebola outbreak: the importance of looking at people as individuals and members of a particular community for finding the best way to provide health care for them.

Exactly right. He talked about growing up in a bilingual and bicultural household and the challenges that presented for him and his family when they went to the doctor’s office. And we also talked about what he has struggled with on the other side of the equation as a doctor caring for patients who come from many different cultures and often speak different languages.
But he also shared some of the improvements that he has seen in the last ten years in boosting cultural competence and reducing health care disparities and shared tips that doctors and patients can follow to raise the quality of care.

**JM:** I had the chance to hear him speak a few weeks ago, and I know that he’s really passionate about this work and has thought a lot about it. And I’m looking forward to hearing what he has to say.

[Musical transition]

**SD:** Joe, thank you so much for taking time out of your day to talk with us today.

**JB:** It’s my pleasure; thank you for having me.

**SD:** So, you are the director of the Disparities Solutions Center here at Mass General. What do you do here?

**JB:** So, the Disparities Solutions Center was created in 2005. The basic genesis of the center really grew out of a lot of research, work that I’d done, but a lot of work that had been done nationally, that really put on the health care map the issue that if two patients present to the emergency room, all things about them being equal except for the color of skin, and they both presented with chest pain, one patient might be less likely to be referred for cardiac catheterization, angioplasty, bypass surgery or cardiology specialist care.

If you have two patients, again all things being equal about them, including insurance, socioeconomic status and the like, except for the color of their skin, and they both present to an emergency room with a broken arm or a broken leg, minority patients are significantly less likely to get the same amount of pain medication for the same exact fractures as their white counterparts. This is an area in health care that we call racial and
ethnic disparities in health care. These are differences in the quality of care the patients receive when you particularly look at this issue of race and ethnicity.

Now, there are disparities in other areas if you stratify by socioeconomic status, insurance status, gender and the like. But the research on racial and ethnic disparities has been particularly, I think, poignant. It’s been massive and my sense was, in the early 2000s, that there was a lot of research being done in this area, but a lot less action and a lot less focus on doing something to better identify and address these problems.

**SD:** Talking about it, studying it, but maybe not putting it into practice?

**JB:** Exactly. And so the center really tries to fill this gap. We were developed and created with the explicit purpose of working with operating health care systems, and users, people who are delivering care systems that are designed to deliver care; health plans, hospitals, health centers, to get them to, number one, be aware of this issue and to put it in the context of all the other things that they’re doing.

Number two, to build the tools and skills they need to identify how disparities are impacting their care and were it’s happening with a particular focus on its link to cost, quality, safety. I mean, we want to really make this something real for health care leaders. They deal with a lot of things; we want to really link it to these issues that they need to be responsive to. And then at the end, giving them some tools and skills to do something about it. That is our main goal.

And so the center really does this in a variety of ways. But we want to create a national movement, create momentum, that’s built on tools, skills and action.

**SD:** Now, you became interested in this, I understand, at a pretty young age because of experiences that you had with family members interacting with the health care system. I’d love to hear more about that.
**JB:** Yes, so I’m originally from Puerto Rico, grew up in a bilingual, bicultural home. Had the good pleasure of growing up in two cultures and being able to speak Spanish, certainly, but also seeing the perspective of some of my family members and how they viewed health and health care. How they brought their own health beliefs, values and perspectives to the table. How those are often at odds with what doctors would say or share with them. Getting a chance to go with my grandparents to the doctor to serve as their interpreter. To really see that some of the challenges that people were facing were common to all people, but just to varying degrees.

But there was no doubt that if you throw into the mix different cultures, perspectives, language barriers and the like, that these challenges, I think, impact certain populations more than others. And we see that in the literature. So this work comes from a very personal place. It’s from my own personal experiences with my family serving as an interpreter for my grandmother, seeing some of the challenges she faced despite having caregivers who cared deeply for her, seeing this again in medical school play out.

You know, I think I decided that I wanted to just simply figure out how we could create a health care system that could better meet the needs of all patients, not just a select few. And I think that’s an aspirational, universal message that people could rally behind. I think that’s what we found. But there’s no doubt that people feel like, and I personally feel like, the more passion you bring to this, the more effective you are, and people see that. And I think they see it’s not—this isn’t for me an academic pursuit, this is about people’s lives.

**SD:** Can you tell the story about what happened when you went with your grandmother to the doctor one day?

**JB:** Yeah. You know, and this story is something that I think we’ve all seen as caregivers where you show up with a family member and are asked as a child to assist in that process. And oftentimes, like in the case of my grandmother, the family member really liking the doctor so much and viewing the doctor as an authority figure, that even if
she didn’t understand, or even if she had questions, she didn’t want to ask because she didn’t want to disappoint the doctor, or she didn’t feel like that was her place.

And so a lot of times, we see these visits, and my visits were no different, where no matter what the doctor asked the patient, my grandmother will say, “Yes, doctor, si, doctoro, si doctoro, si doctoro.” And at the end of the day they leave the visit and say, “Well, I’m not really sure what they said. I’m not going to do it anyway.” And it’s not because—it’s not about liking or not liking the doctor. In fact, it’s quite the opposite. My grandmother really liked a lot of her doctors. We see patients who really love their doctors, who rate them very high on patient experience, but their cultural view is, “I have to behave well in the visit. I have to do what’s told to me. This isn’t about me asking questions. And I like them so much, I don’t want to disappoint them.”

So the “yes, doctor” phenomenon is something that’s universal. I experience it, other people experience it all the time. And I think we could do better.

SD: Have you then experienced a situation like that from the other side where you’ve been, I don’t know, either a patient or a health care provider and you’ve had to deal with these sort of cultural communication barriers?

JB: Yeah, all the time. I really care deeply about cross-cultural issues in health care, and I try and employ these skills all the time. I’m a practicing internist. I spend around 30 percent of my time practicing primary care and internal medicine. But here we see an incredibly diverse population. I have a lot of patients who are from Haiti, from Cape Verde, from Italy, from Portugal, from Brazil. So my Spanish helps me for about 60, 70 percent of my patients, but there’s another big group for whom cultural barriers—Irish patients—for whom cultural barriers, perspectives, in some cases language, plays out in front of me.

And so I need to be attentive to making sure I bring in an interpreter, that I guide the visit. That I really create a safe space to say, “Hey, it’s okay if you ask me questions.” I
say, “I’ve given you a lot of information. Let me know if you have questions right now and tell me what they are.” So really try and encourage the dynamic to not be, “Do you have any questions, yes or no?” But, “Hey, I expect questions, and they’re helpful and that’s good.”

So these are all tools and skills that we learn that could help us be more effective and that are practical and actionable. These aren’t about making the visit two hours long, which we just can’t do. This is about having a set of tools and skills that allows you to do better.

I deal with that all the time and I’ll say that there are situations, certainly, where patients want family members as interpreters because they don’t want somebody else coming in. Those are challenging because you know that an interpreter is a lot more effective and trained, and the like. In an effort to respect the family’s wishes, I’ll sometimes use family members. Never use children, because I tell them that’s not possible. But if I use a family member, I make sure that we cover certain things and only certain things. That if I’m going to go into sensitive areas, I require an interpreter.

And that I’m going to guide that family member. Hey, it’s not just about editorializing. Like if they give a long answer, don’t just say they said it’s fine. Really give me everything they said. You’ve got to give people some guidelines. So those are ways that I manage these things in my clinical practice.

**SD:** So are those the kinds of things, too, that doctors should be aware of in their daily practice? Like, how can they better serve their patient populations as demographics around the country are changing?

**JB:** Yeah, this is the whole evolution of this field called cultural competence, which really focuses on how do we make sure that our patients get cared for at a high level, anyone from anywhere at any time? I think that’s quintessential to being a care provider.
Now, a lot of what’s been done in this area is two things, which I think have been faulty. One is try to teach what we call a menu-based approach to culture, which is to try to teach you, “This is how you need to care for the Latino patient, the African American patient.” And I think in many ways that leads to more stereotypes. There is no menu or guidebook on how to care for populations. Every individual’s an individual. So that’s a key lesson we want to teach people.

But the other one is a lot of people feel like education in this area is—“You’re trying to fix me because I’m broken.” There’s an assumption that we’re trying to fix you, or that this is political correctness, and the like. And at the end of the day, what we really try to teach people is there are gaps, there are disparities. What can we do to up our game? We want to teach you some key tools and skills that can be accomplished in a 15-minute visit, that are going to add value to the encounter, that are going to help you with some of your more frustrating cases where you feel like you could be doing something to help the patient, but you just can’t quite get that sense of cooperation.

That’s what we’re trying to teach. And so we are making progress, but it needs to be done in that spirit. Aspirational, key tools and skills, focus on performance, value and high quality care. And I think that’s where we’re trying to drive this field.

**SD:** And you teach at the medical school as well, right?

**JB:** Yeah. We teach here at Mass General, do a lot of work at the medical school and do a lot of work nationally, primarily through e-learning where we’re able to kind of—as opposed to being on the road all the time, I’m able to kind of use case-based teaching in an e-learning fashion and do a lot at that scale: train a lot of people with the standardized dose of education in a short amount of time across the country. And so that’s been very effective. In some of our work, we’ve trained over 140,000 health care professionals across the country.

**SD:** Pretty good reach.
**JB:** Yeah. We think it’s important, and really creating a learning pathway for these people. So we certainly don’t anticipate that one course does behavior change make. We really believe that it is about giving people a set of tools and skills that they could use, that they could learn over time. And I’m an incrementalist. I believe that if I could share one, two or three tools with a provider, they could do three things better tomorrow, that’s success.

**SD:** And is there anything that patients can do to improve the way that they and their doctors work together?

**JB:** Yes, certainly. I think that particularly for the populations that we work with, a couple of key things that we want to share. Number one, take the time to hunt for a health care provider and a system that really meets your needs. I think the last thing a patient should be doing is settling for a caregiver who doesn’t really meet their needs, or they don’t feel really provides good care to them, or they don’t trust. So that’s first.

The second is, as a patient, being prepared. Knowing a little bit about your symptoms. When you present with a complaint, knowing what your medications are, having that history at your fingertips is just going to be helpful.

Number three, not being afraid to ask questions. I mean, there’s no doubt that the care encounter should be interactive. And so being prepared with one, two or three questions. Making sure you leave the caregiver’s office with a good understanding of what you need to do.

I think if you hear these, you’d imagine and you could say, well, these are important for all patients. The answer is yes, but the truth of the matter, for vulnerable populations where mistrust is an issue, where there is this reluctance to ask questions, where there is a sense that, “Well, that’s just my doctor and I’ve just got to work it out” or “That’s where
I need to be seen.” These issues impact them more than others. They don’t have the sense that they can move to another caregiver. They don’t feel comfortable asking questions.

They maybe don’t think they should be prepared, that it’s really in the doctor’s hands. So I think these tips can be especially helpful for vulnerable minority populations.

SD: And what are your hopes for what can be achieved in the next 10 or 20 years?

JB: Well, I think we’re certainly moving towards a health care system that in a much larger way acknowledges the importance of personal characteristics, in general, on care. Whether it be race, ethnicity, gender, sexual orientation, disability, veteran status. I mean, this concept of big data, understanding who people are in a deeper way, is one that I think is going to move the health care system to be truly more patient-centered and to better understand who we’re caring for and what we could do for them.

So I think that’s very positive because disparities will fit into there. I think that’ll be incorporated into how we’re providing care. I do think we’re moving into an environment where there’s more focus on measurement, monitoring, identifying gaps. And we’ve done an incredible amount of work nationally on patient safety. My hope is that similarly the issues of disparities and equity could follow that model where we monitor safety events, we monitor errors in a nonjudgmental way, but in a spirit of learning. I think we’re moving towards—in that direction in the next 10 to 20 years around disparities.

And I feel like health care transformation will allow us to do a lot of things that we know work and have been particularly helpful to address disparities such as the implementation of coaches, navigators, community health workers, but haven’t had a way to finance previously because of the way our health care system paid for care.

As we move towards paying for quality, I believe that we can take all those lessons learned from what we’ve deployed and they will make financial sense now. You know, so many great programs have died because the foundation now is no longer funding
them, because the contract is over. With this fundamental shift in the way we pay for health care, we believe that won’t be the case anymore, and we’ll really be able to fund things that work and sustain them.

SD: I look forward to seeing some of this begin to happen.

JB: Yeah, as do I, and I’m excited to be part of the process and trying to groom people as well who can continue this change and action long after the Disparities Solutions Center fades away.

SD: Well, thank you very much for taking the time to share some of what you’re doing here and how you’re trying to help patients all over.

JB: My pleasure. It’s been a real joy and I thank you for inviting me.

SD: Thanks.

[Musical transition]

SD: And now for this month’s abstract.

JM: When a diamond miner named Sahr arrived at the Ebola treatment unit in Kenema, Sierra Leone, in 2014, he saw red fences surrounding the area where people with suspected and confirmed cases of the disease were to be treated. He panicked.

The colorful barricades reminded him of the horror he experienced in 1996 as a child soldier in Sierra Leone’s civil war, when rebel fighters used to attach red cloths to their guns during live battles.

Personal details like this aren’t just colorful anecdotes from the Ebola pandemic; they’re important data in the kind of interconnected, multidisciplinary study that’s necessary to
understand the outbreak. They’re also key to building the kind of health systems that will prevent a repeat of the deadly events that unfolded in West Africa from 2013 to 2016.

The study was led by Paul Farmer, head of the department of Global Health and Social Medicine at HMS, and Eugene Richardson, a physician and research scientist at Partners In Health in Sierra Leone.

The researchers used the survivor stories to trace the connections between the closing of schools during quarantine and the rise in teen pregnancies in the nation; between the deadly toll of Ebola on caregivers, and the rise in deaths from unattended childbirth and malaria—all in the context of a nation ravaged by civil war and a brutal legacy of colonialism.

As the authors point out, understanding the social, cultural, historical and economic environment where the outbreak occurred is just as important as understanding the biology of the disease and developing effective treatment plans.

To build a working health system, all of the pieces need to fit together.

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SD: This podcast is a production of Harvard Medical School’s Office of Communications. Thank you for listening. And thanks to our producer, Rick Groleau.

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