The power of our voices: Thinking about the language we use in medicine, and the positive consequences of open notes. With Dr. Leonor Fernández.

Medical notes capture information that informs decision making. They can also reveal how healthcare providers are judging their patients, and patients reading those notes can feel offended, shamed and stigmatized by what they read. Since the enactment of the bipartisan 21st Century Cures Act in 2021, U.S. federal law now gives everyone the right to read clinicians' notes in their electronic medical records, a process called open notes.

Drawing from her work as a Latina primary care clinician and health equity advocate, and as a Harvard Professor, Dr. Fernández highlights the importance of language and culture in medicine and in our medical notes. In this episode hosted by Dr. Minerva Campos, we explore how language and literacy shape our ability to offer equitable, meaningful, and respectful care to Latinx, Black and other marginalized populations. We also discuss how transparency is a positive force for equitable care, and explore ways that engaging patients, communities and diverse staff in the design and language of health care is essential for positive transformation.

Dr. Campos: Hello. Welcome to the Health Disparities podcast. Where we have conversations about health equity. We are taping this podcast live from the 2021 Movement is Live National Caucus, held in Washington, D.C. every year. I am Dr. Minerva Campos, a member of the MIL steering committee. Today, we are going to explore how language and literacy shape our ability to offer equitable, meaningful and respectful care to Latinx, Black, and other marginalized populations. We are so happy to have our guests here today, Dr. Leonor Fernandez, assistant professor of medicine at Harvard Medical School. She's a senior advisor for health equity at Beth Israel Lahey Clinic and the director of Patient Engagement for the Health Care Associates with Beth Israel Deaconess Medical Center. Welcome, Dr. Fernandez. So nice to have you. We just heard her plenary, and it was absolutely fabulous. Could you share with our listeners the main subject of your plenary and what were some of the key points that you made?

Dr. Fernández Thank you so much for that wonderful introduction and thank you so much for inviting me here to this incredible session of Movement is Life. It's been a wonderful two days. The plenary session I did was called, "The Power of Our Voices," and really it was highlighting the importance of bringing up certain voices and of highlighting language in order to achieve equity in health care. And so basically, I did sort of a little bit of a whirlwind tour, talking about what language-based obstacles may exist in accessing care in our country, how we might approach those, and then more broadly about the importance of language, metaphorically. How it is so important that we speak the language of patients, be it in English or in any other language, and reach them where they are. So, I made a number of other points, but that might be, perhaps, the biggest focus was on how systems and clinicians need to organize ourselves, in order to be effective in delivering equitable care and that there is no quality without equity.

Dr. Campos: And one of the things I heard you talk about that I was so impressed with was that you've been doing work with patients really your entire professional life. You do hands on clinical care, you're Spanish speaking, and so you work with a lot of Spanish speaking patients in the Boston area. And you've come to what I believe sounds like a philosophy of care through your patients, by listening to their stories. And I want to hear a little bit more about that. I know that early on you worked with Open Notes. Could you tell us a little bit about Open Notes and what kinds of lessons did that bring to you?

Dr. Fernández Absolutely. Open Notes refers to the concept of sharing notes with patients, and in our institution at Beth Israel Deaconess, we started doing that already about nine years ago at this time, and several other institutions and hospitals had been doing. So, since April of this year, after the Cures Act, it became law that all health systems actually have to share, not only notes, but also lab results, pathology results, all of these things quite immediately digitally with patients through a portal or otherwise, if they so want to access them. I learned a lot from my work and experience with Open Notes. I learned that sometimes we in the health system are perhaps too paternalistic or maternalistic, whatever you might call it, in that in our thought that we need to protect patients from how things may come out in notes, in labs, we thought it was better not to share these things immediately, and I was actually initially a little bit surprised by my own trepidation and that of many other clinicians. But my instinct was that this is the right thing to do. And not only that it was right, but that it will help start aligning what clinicians do with what patients need. Because if patients quite early on have access to how we describe an encounter, it sets up a feedback loop that in the end will be quite positive for accuracy. It sets up a feedback loop for making sure that we maintain a respectful tone about patients, not just with them. So, what we found is that, by and large, patients love it. They love having access. Not everyone wants to access their notes, but they want to be able to. It's an interesting distinction, and they feel more in control of their health by being able to access their notes. They feel they might understand things a little better and they feel more trust with their clinician and their health system. So, I think it's a positive thing. We did learn other negatives. I don't know if you want me to share.

Dr. Campos: Yes, please.

Dr. Fernández So, what we learned is that, like any new thing, you have to think about what you might need to change once you introduce a new technology or intervention. And what we found is that one out of ten patients said, in a survey that we did of over 100,000 patients who were using shared notes, one in ten said that they found something in a note that they either felt judged by what they read in the note or that they were offended by what they read in the note or both. And when you dig down deeper as to what was it that made them feel that way, what they said was that they either found errors in the note or that they felt disrespected or that they felt labeled. And what it prompted me is to really think about some of the language we use in medicine. And let me give you some examples. We say without thinking, she denied this, right? Like, I don't even think about what she denied. Chest pain. She denied. Well, patients read that as us saying she denied alcohol use. Are you trying to imply that I was denying it, but it wasn't really true? And so, there is embedded in some of our language, a degree of skepticism, a degree of not necessarily partnering with the patient. More importantly, there were issues around obesity, drug use, descriptions of pain in which our notes stigmatized the patient and blamed the patient for their current condition. So, long story, but that's exactly why we're learning that we need to use more partnering language in our notes. These are very slight shifts in how we speak, and I think having to think about that will have an important effect on clinicians being able to take the patient's point of view.

Dr. Campos: I like that, and I can imagine there's been some resistance to hearing that from providers and I wonder how you have handled that. Is it something that people seem to want to hear or is it just fear of not knowing how to do it, how to put notes together that don't offend patients or don't stigmatize them or don't, you know, I think it's the physician that has a rush to see a patient and is so used to a certain type of language and way of

describing the way they're seeing it, that they're not really capable to think the way the patient might be hearing it. So, what kinds of things have you done and gotten involved in within your own institution to sort of give other providers the information, especially those that really want to tackle this?

Dr. Fernández Yeah, it's a great question. I think clinicians and health care staff in general are so stressed these days and sometimes this can feel like one more thing you're asking me to do, and people are already sort of up to here and it's hard. The weird thing is that, in general, I was wondering if it was working when it got turned on in my system. I heard nothing from my patients about my notes being, and this was before I changed anything in my notes, I hadn't done a single thing, I just was doing my regular notes, and I never heard any significant feedback. It's actually rare, and that is the experience. It's extremely rare to get a lot of feedback about your notes. So, in terms of the operational flow, people are afraid they're going to get like clobbered with emails and phone calls about, why did you write this in my note, that's actually not what ends up happening because I think, by and large, the act of transparency in and of itself of sort of like when you shift the computer so the patient can see the screen, it invites a certain trust so that, by and large, patients appreciate that. I think what patients really judge you on is whether you're kind in the office. I actually don't think the note weighs enormously in their general opinion of you as a clinician.

That said, I think that they may not voice it, but there are certain things that they're like, wow, a little bit, why did they say that? So, I think we just need to educate ourselves, just like we've learned other changes in how we refer to certain congestive heart failure now or how we… It's just educational. It's just learning a little bit of what is more effective as a language. And then there are ways in terms of software that we can facilitate that as well within the software embedded within our electronic medical records. But I think the general principle of feeling like you have a patient right near you as you write a note, while there may be a tiny element of burden, it's the right kind of burden. The burden we should be getting rid of, in my opinion, are the ones in which notes are being asked to be a million things, including primarily an auditing and billing instrument. That is what we need to get rid of. Then notes can shrink, can have less note bloat, and I can really and you can really use them so that I can more efficiently transmit the required information of what happened in this visit that is relevant to you as the covering doctor or the next specialist. So, I think sometimes when you come to clinicians or others, there's a vent of like, don't come to me with another thing, but I think that we should be thinking about whether that's the bad thing. The bad thing may be something else that we're feeling stressed about. It's really not about patients sharing the notes. I don't think.

Dr. Campos: I think you're right. You know, most people give one the benefit of the doubt, in particular when they've had a really good encounter with you. It seems to me that what you do by sharing is that you make it more of a conversation between you and the patient. And so, it's in their own words and in your own words sort of become how you communicate, you understand them, and they understand you. So, I just really like that approach. But I can see why people might be a little bit hesitant and worried that the nice encounter they had with their patient is going to come back to haunt them. But I really approve of that approach, and I hope more and more people take it on in this transparency. They have to begin to embrace it.

Dr. Fernández I agree. And I think now that it's law because it was found to be so helpful for patients and then it kind of is just part of the picture nowadays. So, I totally agree with you.

Dr. Campos: Now, one of the things that I've I noted is that all of these ideas that you've had and how you've worked through them have kind of come to bear with when COVID 19 hit us. And all of our hospital systems have very difficult to reach patients, patients that don't speak our language, who don't have access in the way we wish they did. Can you tell me how you were called on or called upon to help your system reach patients with different languages besides English, and how it helped them reshape their campaign in getting patients to hear the messages about COVID 19 vaccines in particular?

Dr. Fernández What we found in our health system, so we were charged with distributing vaccine starting in December 2020 and then January 2021. And what was amazing was that our CEO, and our leadership had articulated already, earlier in the prior summer, a real commitment to wanting to reduce racial and ethnic disparities. And that set the tone. And that allowed a lot more traction that along with the terrible realities we were seeing with the disparate kind of impact of COVID on marginalized communities with lower socioeconomic status, communities of color. And so, suddenly, the traction factor in this past year for a lot of voices that were trying to build the conversation around what sort of systemic changes need to happen in order to serve our communities more broadly. That traction really increased so much, and there were many more voices in the rooms making decisions. So, our system formed, like many other systems, what we call command center. And for vaccination, we had a vaccine command, and that allowed a more centralized decision making in which we brought a lot of different disciplines, roles to the table. And in that conversation, there was interest in thinking about what would be effective to reach the populations you just mentioned. And so, we had to do so much homework, and honestly, we found we were so behind first from using what has been called real data of race, ethnicity, ancestry, and language to sort of know who our patients are and then to strategically deploy communications to those groups. And so, basically, we had to learn how to quickly translate things. We had to learn that to reach people, you can't only rely on digital outreach, but when you do use digital that you need to use SMS, not just email, and that there's nothing like the power of trusted messengers coming from clinics, clinicians and community-based organizations for certain communities in their own language and from places that they're familiar with and have known that are looking out for the interests of that community. So, basically, a combination of all of those factors, we use to start outreaching to the diverse communities we were serving.

Dr. Campos: So, that's really interesting because I'm wondering myself whether the kind of work that I think systems found themselves having to do, clinics found themselves having to do is had a lasting effect on how we will deliver care from now on. And some things have been exposed to us that I think we sort of always knew. But there wasn't the urgency to really, at least by the heads of the hospitals and systems to correct. So, what do you think? Because one of the questions I did want to ask you was, how optimistic are you, you know, that we as a country are heading in the right direction in tackling health disparities? And do you feel like your system has learned a lesson that they will continue to develop systems that now will include in a more effective way the populations that we're concerned about, populations of color and patients in poor socioeconomic status. What do you think?

Dr. Fernández In terms of our system, I'm quite optimistic that we're moving in the right direction. We have a new chief diversity equity and inclusion officer. H his name is Juan Fernando Lopez. He's fantastic with great support from leadership of the institution. I think that really matters, right? If there is sort of that setting of the stage of what's the goal moving forward from high up in leadership, I think the chances for success are much more. I think systems change, especially big systems. A lot is required to change them. They have more inertia. They're like the Titanic. So, I think that it requires accountability. And so, I think what will be key is setting up mechanisms of accountability for these organizations in doable ways and then resourcing them. And so, in our institution, we're thinking a lot about how we will do accountability and how will we measure progress in reducing disparities. I think at a national level, I think this has been a wakeup call that many of us knew these issues were out there, but it's been such a wakeup call, globally. So, I think part of what will determine whether we're all moving in the right direction will be based on whether we have the political will to do hard things, and whether we have the political will may be beyond the scope of what I have the expertise to comment on for the nation, I'm hopeful, but I can say for our system that I think new voices, new people are in the room where it happens.

Dr. Campos: I think that is great. And this has been such a wonderful conversation. We could go on forever, or at least I could. I do want to ask you, though, you've been attending our caucus meeting, and this is the first time that you have actually come to this meeting. So, it was wonderful to have you. And what impresses you most about the caucus? What have you enjoyed about the caucus and what will you take away?

Dr. Fernández Well, I think it's inspiring, the motivation, the passion, the commitment of the movement itself and the executive leadership, the organizing committee. I came to this through Dr. Gus White, who I then found many other people in the room who had come to this through Dr. Gus White, who's just someone who is so generous and visionary in cutting across the silos of disciplines. And so, one of the things that I found inspiring is to see my orthopedic colleagues, to see lawyers, to see physical therapists, to see such different disciplines and nursing and patient advocates come together, and to see orthopedics and musculoskeletal take a lead on disparities, which I think a lot of us would have stereotypes that would not place them in the lead there, right? I just find that inspiring. I think whenever something surprises you, you should always think about what beliefs were you holding that made that surprising, right? So, it has made me rethink some things, and I just have found it just a joyous occasion. And I've learned a lot of specifics from our speakers here. So, thank you so much.

Dr. Campos: Well, we've learned a lot from you. So, you also have been inspiring to us. And I want to thank you on behalf of Movement is Life, it's just been wonderful to get to know you and hope we see you again in our caucuses. And thank you very much for this wonderful conversation.

Dr. Fernández Thank you, Minerva. It's a joy. Thank you.

Produced by Rolf Taylor for Movement is Life