The Beginning of Health Literacy and Then Some: A Talk with Yolanda Partida, Founder of *Hablamos Juntos*

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It all began when María Cornelio, author of *Translating Spanish for the US, What Are the Challenges?,* realized that the *Hablamos Juntos* website was offline and could not be used as a bibliography source. We were intrigued. How could such a groundbreaking source of research and information have disappeared? How could we carry on where they left off? We decided to contact its founder, Dr. Yolanda Partida, who was kind enough to talk with us in the middle of a house-moving environment. We requested an interview and Ms. Partida, in turn, asked us to give her a RIUSS statement and three questions. This is our statement:

> We recognize the value of *Hablamos Juntos* inroads in improving healthcare communication through translation to reach LEP Spanish-speakers. We share the same goal and want to expand on that applying a scientific research method to help provide unity and standards to all communication resources involved. We would like to transition from consensus-based to evidence-based.

Yolanda Partida brings 25 years of experience in public and private health administration as national program director for Hablamos Juntos, an initiative that examines language barriers to health care for Latinos. She has worked with and on behalf of many different groups of underserved populations, including the uninsured, the U.S.-Mexico border population, and other ethnic communities. Partida has served as deputy director of community health for the San Diego County Health and Human Services Agency, assistant director of ambulatory care for the Fresno County Health Services Agency, and senior manager with The Lewin Group, a private policy, research and management consulting firm. She also served as a member of the Institute of Medicine's Committee on Communication for Behavior Change in the 21st century, which published "Speaking of Health: Assessing Health Communication Strategies for Diverse Populations." Partida is founder and executive director of The Partida Group, a health policy, research and management consulting firm specializing in diverse populations. Currently, she is working on two expert panels convened by the Joint Commission on Accreditation of Healthcare Organizations to learn how hospitals are addressing cultural and linguistic issues that impact the quality and safety of patient care. Partida holds a doctorate in public administration.

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So, in order to start at the beginning, our first question was about the birth of *Hablamos Juntos*. We knew that it became a reality through the Robert Wood Johnson Foundation ("RWJF"), and Ms. Partida explained how it happened.

LM: How did you get the Robert Wood Johnson Foundation to fund *Hablamos Juntos* as a national initiative?

YP: I met the RWFJ through the officer who would be in charge of my initiative at a conference, serendipitously, we were just sitting in the same row. As I had briefly talked to Dr. Ross, one of the speakers for whom I had worked, when we sat down for lunch, the RWFJ officer asked me how I knew Dr. Ross. She then asked about my background and what I was doing then. I told her that I had been working with Dr. Mary Joy in San Francisco, someone she also knew. Dr. Joy had asked me to do independent consulting work for them– The Lewin Group, a national consulting organization—on health issues. I was introduced to them through Dr. Ross, with whom I had been working at the San Diego County Health Department. At that point, we already knew that the Lewin Group's office was moving to Washington, DC, so we talked about when would I go to Washington, and she asked me what was I planning to do after the San Francisco office was closed. I told her that I would be working on my doctoral dissertation for one sabbatical year and that we could be in touch.

At that time, the Foundation was working on two projects and the officer would periodically e-mail me questions about what I thought about different matters. About a year later she asked me if I would be interested in coming to Princeton, NJ to visit the Foundation. So, I went to visit them and met with several Foundation members and principals, and we learned about each other's interests.

So, she finally told me that they had gotten approval for a $30 million nationwide initiative on Non-Financial Barriers to Healthcare, and she asked me what would I do with that. Then I told her that the focus should be on language in healthcare, because the risks for both the practitioner and the patient are fairly enormous and it is generally not well understood what those risks are and what to do about them. And, in my experience I also learned that there were no translation quality standards, so even when you thought that you were doing something right, you were not sure whether what your intent was, was being carried out in a professional and competent manner.

It was a scenario that had not been looked at and with a growing number of people who do not speak English and the cross-language issue being a problem… Not to mention the health literacy part of it. These two issues combined are a ripe area for new research. So, she asked if I would be interested in helping them conceptualize an initiative. I said, absolutely! So, that was how I became a consultant for the Robert Wood Johnson Foundation.

Language as a risk factor

The first item was to conceptualize that language is a risk factor in healthcare. They came with a model demonstration science, and I thought that the settings would be different and the challenges would be different. We first discussed if we should focus on a singular place, so that it could be studies in depth, but the Foundation preferred a broader vision. So, we concluded that we should look at different kinds of organizations. So, we included hospitals, clinics, health plans, as places where the language challenge would be identified and people would actively try to find solutions. They came back with a model that would be applied nationwide.

Nationwide, because communities are different, how long the necessary resources have been available is different, the understanding of the issues is different because of the experiences, and also because of the kinds of things that people need. The kinds of communications that people are going to have in a community clinic are quite different from those in a hospital where they need to sign consent forms for procedures, or wait in the Emergency Room. Thus, we looked at diverse settings and chose sites based on that. And regionally it was also important because the language populations were different.

We debated whether to do more than one language, and I argued that we do not know enough about the challenges, so let's stay with one language. We will then know if it can be applied to other languages. We thought that at the end we would know what types of resources may be needed, even if the languages are different. So, we looked at it from a very high level as to what we were trying to achieve.

Focusing on the risks, physicians had to be challenged

We got a call for proposals and we received several hundred applications from around the country. We developed an advisory committee and the Foundation was very instrumental in putting together the leadership of the advisory committee. So I ended up working with Dr. Nelson, who had been the executive director of the association that is concerned with internal medicine, the general medicine domain of physician care.

We knew that physicians were going to be one of our primary barriers because they were feeling overwhelmed. They couldn't see how could they handle the standards that were being proposed at that time. So, we decided that we were going to understand better what type of work physicians do, what was practical for them to do the things that we can tell them about how to handle certain issues. We had to challenge the idea that they could handle this on their own. We needed them to understand the risk of using hand signals or bilingual children as interpreters in a physician-patient setting. We wanted them to understand what these risks were.

We focused on this problem at a very high level. We weren't trying to solve a particular problem; we wanted to shed light on the risks and why people should be concerned. A lot of

my early time with this was spent with Dr. Nelson and other Advisory Committee members, meeting with national organizations that had been dealing with this problem by presenting materials in more than one language, doing workshops on what to be aware of when you encounter people who don't speak your language. And that activity intersected with the other new emerging concept which was health literacy.

When a physician or a health provider is telling people what they see as a problem, people are nodding their heads. This doesn't mean that they are comprehending or agreeing with you. It's just a natural reaction to a conversation where you may or may not understand what is being conveyed. It may be just an acknowledgement and you cannot make assumptions based on that. That whole idea really threw them into a loop because it exposed the risk factor to them and the responsibility that they had, that they didn't see they had the resources or the ability to challenge.

What is a doctor supposed to do? Not treat a patient? This is where they were coming from, so they were very, very hostile and upset. So, we challenged them. Either you come up with solutions that work for your particular kind of division or… We visited all the national organizations in their different divisions and their response was equally frustrating.

Why don't these people learn English?
In many circumstances that opportunity may not arise when you are faced with them; so, whether we think that's the right thing or not, at the moment that's what you are dealing with. So, let's focus on that, what can be done at the moment, and you now have this challenge. Let's look at this from a higher level, and let's not ignore it. At this time, this is what happens and we are looking at what happens when you have that encounter and what can you do that's feasible and reasonable and meets your beliefs, your oath to care for people in the best way you know how.

At the beginning, they were hostile, but at the end they became very progressive and they were trying to show that they were going to outdo anything that we might come up with. This was a very positive outcome! Most of the physicians developed committees, and as they saw that we were looking at this issue at that level, and the kind of money that was being put into our well-regarded organization—the Robert Wood Johnson Foundation—that had many physicians, and most of them were physicians with whom I had worked, it got national attention.

LM: How many healthcare organizations do you know that actually use a translation brief and follow the *Hablamos Juntos* Toolkit recommendations?

Before answering our second question, a conversation ensued around the challenges for translators who do not receive clear instructions, let alone a translation brief, and have to deal with monolingual or bilingual client employees. We agreed that bilingual employees were the major obstacle, as they would generally have a conversational level of Spanish that would not meet the requirements of written material.

On this matter, Ms. Partida recalled: "One of the benefits that my experience brought to the table was that I had been a medical social worker for ten years before getting into hospital administration. At that time, in the mid-seventies, out of graduate school, medical social workers were emerging as a requirement, and at least there was recognition at the national level that language differences could present a risk at hospitals. And this was a time when hospitals did not have limits on funding."

LM: What was your doctoral dissertation about and when did you submit it?

YP: My Public Administration doctoral dissertation was about non-financial barriers to healthcare, and I submitted it in 2001.

LM: And did it cover language?

YP: At that time, my thinking about communication in healthcare was much broader than just language. It was about the concepts that were being used in healthcare, what we now call **health literacy**, that was also emerging. But in reality, my dissertation was looking at how we communicate, and I took samples from five locations. I was not looking just at language, but the concepts, words and understanding that an ordinary person would have when confronted with a setting with which he or she was not familiar—terminology and customs that were unimaginable in the average person's world.

And how were the actors, the patient, the physician, the nurse, and whoever came around this, how was it like, what could we learn. It was a case study that was looking at five settings, and what we found was that there were common things that crossed the spectrum, but that there were also nuances that were different, depending on the setting, the resources, the topic, the choices that people had to make. All this made a difference, but there was no easy solution.

The recognition that you are communicating may not be correct. Just because people are nodding their heads does not mean that they are saying that yes, they agree with you or they will follow the plan that you are describing. Nodding is just a natural response, a courtesy. And that language and culture influence how people talk about, how they present you information, how do they prioritize. Then I laid out these variables that were interfering or producing unrecognized tendencies. **So, we learned that we cannot make assumptions. Validating became important, asking people to come back and say it in their own words**. Those were some things that I was not smart enough to recommend; since then, however, I've learned how important they are.

LM: In the *Hablamos Juntos* Toolkits, the matter of assumptions is a key concept to understand how to deal with communication in a healthcare setting. It is very well presented. It does not provide great detail but it's there, and we translators know. We have to ask ourselves what are the assumptions, how do we know if they understand this or that, or how

much more should be said that is not in the source text because it's assumed that yes, these people already know this, but you don't know if it is the same in the other language.

YP: That may be why the Foundation sought me as a potential resource. I dealt with translation before translation was recognized as a field very early on, and it was very common sense—you find what you want to say to these people and you find someone who can say it in another language. But I also confronted them with health literacy, the concepts and the ideas that physicians were interested in, and I had to learn. So, in order to understand, I asked a lot of questions. It took me 10 years to do that, so it took me a very long time to understand what was the role of the physician, and this was just in a children's hospital, with very limited topics.

I became proficient in helping people understand critical childhood diseases, risk factors… because I had to do it over and all over again. And from the parents' perspective it was like talking to my own mother, about body parts and functions. Their vision, their framework, where they were coming from, it was totally foreign. So, the words that they said may mean or not mean that they understand. It does not necessarily mean that they conceptually understand, that they can visually see what you are talking about. And this is why it is so commonly said "It's in your hands, doctor, because they trust you to know what you are doing because they don't have a clue about what you would be doing, but they trust you in your ability to take care of them."

This experience informed my work and I realized that it was much bigger than what I could have imagined. And it was a very small domain to work with. And then you go across regions, you go across communities that speak Spanish, their heritage, the way they speak, regional customs, and twenty-one countries where people come with their languages. And all these factors move medical people to say 'what am I supposed to do with all of that?' You know, I can study for years to figure out what the body needs, an appendectomy or heart surgery; but the total life spectrum, with priorities, values and stuff… it helps you understand how complex it is, and the solutions are not easy.

Methods to evaluate communication

Methods to evaluate communication are emerging as the more practical thing to do. How do you test for what you have said being comprehended by the other person, when they don't have the background, they are fearful, they have had life experiences that made them biased in the way how they understand this. It is all very complex. And you have only fifteen minutes! And this also applies to every one of us, depending on the circumstances and the topic.

LM: Our last question. Given fact that *Hablamos Juntos* has been discontinued, what do you think should be done on the work already completed? But before getting into that, have you seen any use of the translation briefs that you describe in your toolkits, by health organizations?

YP: That is not a new invention. There were folks who were trying to work on that. Consider the background of folks who worked with this, who ended up with these responsibilities, their backgrounds influenced how they approached it. So, if they come with a science background or one where a rigor of accountability is important, they will figure out a way to make sure that you got connecting dots that show you what happened and why it happened, and where it comes from. And remember that many of these folks come from nursing, so connecting the dots is really important. This concept, to make sure that you get consistency over time, so that at least you can have a chance to standardize something and know what to expect… because the spectrum was so wide. The client is coming from various points of view and their issues would be different. That's why health literacy is so important, and I don't see people doing that.

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LM: Yes, it is very important. The Agency for Healthcare Research and Quality (AHRQ) has health literacy tests that should be incorporated as a baseline in all health-related research. And healthcare organizations should always do these tests to determine the level of health literacy and reading comprehension of their patient base.

YP: Yes, follow the Roundtable for Health Literacy. These are people from all walks of life, many with a medical background, representing organizations, sometimes medical specialties, sometimes nursing and more broadly. They publish everything they discuss. They are a good source of information.

LM: We in RIUSS come from a different background. You come from the actual medical working field. You were a medical social worker, which is a very specific area and you are very much in contact with everything in the clinical environment. We come from the language perspective, although we are aware of the need to understand all these other considerations, because when we have to do a translation, these issues arise. That is, if you are conscientious and want to achieve effective communication. Normally, the business side of translation provides a different product, something that is "correct" but may not become effective communication where it is most needed.

What we want to do is research that begins by applying the AHRQ health literacy tests as a baseline and then using your toolkits, that we will have on our website as a resource, clearly showing where these come from. And we will try to promote how these resources are used, so that translation actually becomes effective communication. These resources may help hospitals and health centers hone their communication practices and policies. At least a sector of their patient-base may be identified as individuals who may not be capable of receiving information as readers. Also, other forms or more visual and verbal communication, such as cards or videos, may be addressed to cover their informational needs. And this is the scope of what we would like to do right now.

YP: Yes, the focus on health literacy is very important. It helps elevate the seriousness of translation, because you touch the knowledge that you are trying to breach. This covers the

language of the patient, the very complex science that the physician needs to convey, and the complex structure of the health system. How to navigate the system needs to be a translator's domain. And to that you have to add the complexity of the countries that patients come from, their preferences.

Physicians who participated in the Health Literacy Round Table said that they realized that patients did not understand their descriptions or instructions. For instance, their patients did not understand where an appendix is and why it would have to be removed, and what the connection is to the way they are feeling. So, they realized that the patients don't understand their language and that they have to break it down. A lot of good work was done at that Round Table, and it can be applied to translation.

LM: Thank you very much for sharing these insights with us. We'll try to continue with what you started and to add a scientific approach to evidence-based communication appropriate to most LEP patients in this country.