

Podcast Interview Transcript

Douglas M. Hirano & Haera Han

In each volume of the Journal, the editors select one article for our Beyond the Manuscript post-study interview with the authors. Beyond the Manuscript provides the authors the opportunity to tell listeners what they would want to know about the project beyond what went into the final manuscript. The associate editors who handled the articles conduct our Beyond the Manuscript interviews. This edition of Beyond the Manuscript features Douglas M. Hirano author of “Asian American Health Research: What Community Agencies on the Front Line Need to Know,” and Associate Editor Haera Han.

Haera Han:

Doug, thank you so much for your time to talk to us today. I really enjoyed reading your paper. Would you please provide a brief summary of your paper, perhaps including its purpose and some of the main points that you discussed in the paper, for everybody who is listening, to give them an orientation to your paper?

Douglas M. Hirano:

I was basically trying to outline sort of what the research world—the health research world—look like related to Asian and Pacific Islanders from what I call “the ground,” which is really a community-based agency. That’s our agency, which is trying to work on improving the health of Asian Americans and Pacific Islanders.

So the way I approached the paper itself is I talked a little bit about the disparities that are seen—the health disparities in the Asian American and Pacific Islander communities generally, and a little bit about what we know here in Arizona. I talked a little bit about the existing research, and there is a fairly sizeable research base relating to Asians and Pacific Islanders.

And I really tried to focus in from a programmatic, policy, and systems level on what kind of information we would need, I think, to do our job better, in terms of trying to make both policy and program changes that will help Asians and Pacific Islanders attain better health. So that’s the way the paper was approached.

Han:

I was personally thrilled to see such an insightful paper that offers this unique community perspective, particularly on the Asian American health research.

As a community agency, you have worked with a number of other agencies and individuals from the Asian communities in Arizona, I believe, with different cultural backgrounds—and I think you’ve listed Vietnamese, Korean, and Chinese—for a variety of health programs and projects. Can you tell us about how the health partnership described in your article was started?

Hirano:

The agency itself was started through the efforts of just a few people, actually, in the Chinese American community, who had noticed that Chinese folks living here really weren't accessing preventive healthcare. They weren't getting checked for diabetes or receiving mammograms, and seemed to have not a real good knowledge base around prevention and health.

So on their own, they started doing health fairs and screenings and workshops. But realized, fairly quickly, the dearth of health information really wasn't limited to just the Chinese community.

When they started looking into the Vietnamese and the Korean and then, after that, the Pilipino and South Asian communities, among others—it was largely the same issue—that for whatever reason, the kind of information that helps people stay healthy wasn't really reaching those communities. So that's sort of the origin of our agency.

Han:

So a lot of times when we work in a community, it is pretty common that we oftentimes work in a silo. I'm curious to know whether there were any particular challenges to getting any of your partners involved in the partnership that you've been able to create?

Hirano:

I think there were ongoing challenges, with silos probably on a number of levels, but certainly even within the ethnic subgroups in the Asian and Pacific Islanders communities. For instance, even within the Pacific Islander communities today, even though we've been working now for ten years as an agency, we haven't really managed to outreach, I think, very well to some of the Pacific Islander groups.

We've done better among the Chamorro community, say, than the Tongan and Samoan, and we're sort of continuously working on that. We've had, perhaps, better success among the Chinese, Vietnamese, and Korean communities—I think, in part, because the media infrastructure is better within those communities, when we do events, and we're able to place ads in the Chinese, Vietnamese, and Korean newspapers.

That's how we tend to get the word out. If a community doesn't have newspapers or, in some cases—even radio stations as well. It's harder for us to reach those communities. We really have to work deeper into those communities, and sometimes we just don't have the contacts that we'd like to have in some communities.

Han:

So what happens if you have such a challenging situation?

Hirano:

Well, we keep working at it. We use whatever contacts we have. And, like I said, it's sort of an ongoing challenge for us. We've had good success in some communities and not as much in others, but we try to make sure they stay on the radar screen. We call ourselves the Asian Pacific Community in Action for a reason.

We want to cover the Asian Pacific Islander community as well. We like to think that we're trying to reach all the diverse communities, and we're not just focusing on the ones that are easiest to reach.

Han:

One of the things that I've found very intriguing, actually, in your paper was—you were describing the lack of sufficient and sustained funding, as well as health promotion staff issues or health system issues, which all contribute to the health disparity experienced by the Asian population in the United States.

You talked about this dearth of Asian health data or health interventions adapted for the population. Nevertheless, it was great that you were able to get from the Kellogg Foundation for your community health programs.

Can you describe the process you took to get funding for your work? I think that's a really important piece of information that could be useful for many other community agencies who hope to achieve the same kind of level of funding and activities.

Hirano:

So probably a few answers to those questions. For instance, the Kellogg grant that we now have, called Health through Action, which is actually administered through the Asian and Pacific Islander American Health Forum, was a fairly rigorous granting process, where we had to write a letter of intent and full proposal and then have a site visit. And we were, I think, 1 of 8 agencies funded out of about 135 applicants.

And that was really a coalition-building process. Because, in the end, it was a capacity building project that they were looking at funding. So the approach we took was to build on our existing coalition, and look at the deficiencies related to capacity, and try to involve the various constituencies in writing the grant. And, in the end, having to sit through a site visit, making sure that we were all on the same page, in terms of what the community needed and how that aligned, I think, with the grant objectives.

For some of our other programmatic grants—and that one was more around capacity building—for our more disease-based work, Hepatitis B or breast or cervical cancer or tobacco, some of it comes back to being able to generate good data—local data, I think. Those particular awards—the Hepatitis B work that we do was funded for several years by the state health department.

And we think that the ability to convince them to fund us for that work really lay in our ability to put together pieces of data—local data regarding communicable disease rates, data, actually, regarding perinatal Hepatitis B screening.

But that data availability, I think, is very convincing, especially when it's local. So that was important, at least in that Hepatitis grant, and tobacco as well.

Han:

So it sounds like you have diverse funding sources, not just from the Kellogg Foundation, but also from the Department of Health. Can you tell us a little bit more about your capacity, in terms of grant writing?

I think many small grass root organizations sort of suffer from lack of ability, in a way, to compete for funding such as this. And I think just describing and sharing some of your lessons you've learned over the process, in terms of your own capacity building, in terms of your research ability and writing ability will be an important piece of information as well.

Hirano:

Right. So early in the agency's history, they used contracted grant writing consultants. There was no—I mean we're talking about before there were even any staff people for the agency. And the easiest thing to do was to use some consultants, who actually were relatively successful.

When I was hired in 2006, I took over the grant writing myself. And even then, it was myself and three other people. And I actually had done a lot of grant writing in a previous position, so I was well-positioned, I think, to do the grant writing for the agency.

Since then, we've actually started an internal process to teach other staff to write grants—to, in part, unburden me from all of the grant writing, but also to give them the skills and wherever they end up in the work arc, I guess. To be able to do that kind of work, we think that grant writing is an important skill, sort of a lifelong skill once learned.

But for the most part, the agency, I think, was fortunate to have somebody who just had done a lot of grant writing. As you probably know, it's hit and miss, and I learned sort of seat-of-the-pants.

There are other ways to learn about grant writing. But I feel fortunate that I have done enough of it to kind of know mostly what works and what doesn't work.

Han:

In your paper, I think the part that I just can't agree more with was the part where you wrote that: "Producing results in a controlled research environment is one thing. But doing it in the real world is another thing."

I'm curious to know: what are some of your takes on some of the critical processes, if you will, to make whatever program you are developing more relevant to the real world?

Hirano:

For us, the line from the paper was really that sort of adaptation question.

Sometimes what's in the research literature—a good example is the diabetes prevention program that—I think it was a very large study that had shown that if folks with pre-diabetes were—if there was an intervention that successfully had them change their diet and physical activity levels—improve their diet and physical activity levels—that they could decrease their likelihood of developing diabetes—is really hard to replicate in the real world.

Because it was, I think, predicated on multiple sessions with multiple hours of intervention. So it's always been difficult, I think, to try to replicate some things that work when you have the resources and a research project. But you have far less resources in a real world setting.

The approach we've taken, for the most part, has been fairly simplified, I think. A couple of things—one is to check the evidence base. If we're gonna do something in, say, diabetes prevention or tobacco or, say, colorectal screening, we definitely want to check what's in the literature, what the evidence base looks like. We'll go to the Guide to Community Services and see what has worked.

Hirano:

Rarely, though, is that directly adaptable to Asian and frequently non-English speaking and highly diverse, multicultural populations.

And so we will try to simplify, in some cases. I think one of the examples I had in the paper was that we had done sort of a chronic disease self-management workshop called Living Well with a Disability, focused on folks with disabilities, and really had taken what was a curriculum that has been shown, in research, to work among English-speaking American people, and tried to go ahead and adapt it, basically changing the language and actually running our workshops in Mandarin.

So, in that case, that's an active—it's a bit of a leap of faith. It wasn't culturally adapted. We did our best to translate the language, in terms of both the handouts and some of the ideas. But in the end, that was a case of doing the best you can with what's available, which is, I think, what happens a lot of times in the real world.

I think the point I was trying to make with that illustration in the paper really was—well, there's certainly a lot of opportunity to take evidence-based curricula like that.

There is, of course, the Stanford Chronic Disease Self-Management Program, which is very similar—and doing the adaptation and rigorously adapting it to other cultures and other languages. I think that was an area I thought was fruitful—collaboration between community-based organizations and researchers.

Han:

I see. So I think that sort of leads to my next question, especially in terms of that curricular adaptation for Asian subgroups. You are sort of suggesting that could be an ideal project for a community partnership.

Based on your past experience, how did your partnership of knowledge, perhaps, work through these issues of cultural competence and cultural sensitivity? You talked about some of the outcomes, and of procedural steps that you took. Did you specifically include people who have both cultural knowledge and understanding in your group?

Because I can imagine that are multiple Asian subgroups, and sometimes you may come across a situation where you can't really identify anyone who is aware or knowledgeable about a particular cultural group, necessarily, or the language even.

Hirano:

Language is sort of the common denominator. I mean the woman on staff we have here, who taught that Living Well with a Disability course, speaks Mandarin—is actually Taiwanese, born in Taiwan and a very experienced, skilled person. She was a newspaper reporter while she was in Taiwan, but not a trained educator, not an academic, not a licensed healthcare person.

She literally translated, I think, some of the materials. But she wasn't able, I think from an educator's perspective, to culturally adapt some of the curricula and maybe even some of the learning theory that went into the curricula, if that in fact needed to be changed based on cultural orientation.

Hirano:

We use who we have and what we can afford to do. It's not ideal, and in that one case, anyway—we have staff folks who speak Korean, Vietnamese, and Chinese, and in those three languages, we can do something similar.

Outside of that, I think we would be hesitant to try to adapt curricula for folks for whom we don't have staff who can speak those languages.

Han:

So tell us about your program's successes and challenges, perhaps. I know you've talked about some, but what are some of the factors you think have led to these successes and challenges, perhaps?

You said that the Asian Pacific Community in Action, which is the community agency that you are leading, has been around for the past eight years. Correct?

Hirano:

Well, we're getting close to our—well, we're just finishing our ninth year.

Han:

Ninth year. So tell us about your program's successes and challenges. And what are some of the factors you think have led to these successes and challenges, perhaps?

Hirano:

Our Hepatitis B screening program, I think has been successful, in terms of the number of people we've screened. We started in 2006, and we've tested about 2,500 people. No mean feat convincing people—Asian people, who actually have a very high rate of Hepatitis B infection, but don't know it. We're talking about a silent infection, something that doesn't have the kind of symptoms that might drive you to a provider or convince you to get screened.

On the surface, it's highly successful. Out of the 2,500 percent we've screened, about 155 have tested positive. Most of them are people who had not previously known that they were chronically infected with Hepatitis B, most of whom we've successfully been able to refer into medical care. So for those 150 people, lifesaving information was provided, and referrals were made.

The thing that I worry about, I think, with screening programs—and we've done similar programs for diabetes and identified people who unknowingly had high glucose levels or high cholesterol levels. I still worry, a bit, about whether they stay in care.

For people with Hepatitis B, it's important that they find a provider who can monitor them and treat them appropriately. But that has to be over the rest of their lives because B is a chronic, permanent disease. There's no cure for it, at the moment.

Hirano:

So the sort of research question that we would like help from the academic community in answering is tracking people over time, whether they're diabetic or whether they have Hepatitis B, to see whether screening and education programs, the types of programs that we operate, really have that sort of lasting impact for people—that they stay in a system of care, and they get the medications they need when they need them. So outwardly, I think our programs are highly successful.

But the question is: over the long haul, do they improve people's quality and quantity of life? It is a question that nags at me a little bit, that I think should be part of the equation of offering screening services to people.

Han: I absolutely agree, especially sustaining some of these positive changes as a result of health programs that are led by the community, mostly impacted by the particular condition. I think it's really key. Although, as you mentioned, there are a lot of challenges that need to be considered and, perhaps, overcome. But I absolutely agree.

Toward the end of your paper, you talked about community agency role in advocating policy and, also, participating in policy evaluation. I'd like to hear, from you, more about this. Perhaps if you can just share some examples that you can think of as to how.

Hirano: In Arizona, immigration policy has become obviously the hot topic in Senate Bill 1070. Arizona was one of the first states to develop some very hardline immigration policy. And I think all of us should be asking the question: among disenfranchised, foreign-born minority pops, what kind of impact does that kind of policy have on health? We would be very interested.

And we haven't learned, I think, as much as we can or should from our own sort of constituencies—Asians, Pacific Islanders. But the larger question of the impact on Hispanics and other groups, in terms of, I guess, utilization of entitlement services—whether these kinds of policies are creating a chilling effect on utilization and impacting health. It's one thing I can think of that's very timely here and obviously very geographically relevant for us.

The other issue I talk about a little bit—language access is a big issue for Asians and Pacific Islanders. Asian Americans—30 percent are of limited English competency and proficiency, so their ability to access the healthcare system has a lot to do with how healthy they can stay.

There are, through Title VI of the Civil Rights Act—there are existing standards around language access and the ability of—or the requirement of healthcare providers to offer those kinds of services. But we don't know how well enforced Title VI is.

I think there's some interesting research that can go on, as to whether hospitals and doctors' offices are actually complying with the requirements. And separately, whether people in the community are accessing services that are language—language-access type services.

Han: I do have a question as to one of your recommendations in addressing pressing health concerns in the Asian community by strengthening the lines of communication between communities and researchers.

As a researcher, I would be very curious to hear from you, as to some of the suggestions you can provide to see how we can achieve this strengthening of the lines of the communication.

Hirano: I think that the line of communication is at least twofold, in terms of what types of information can go back and forth between researchers and communities. The first would be instructional.

Hirano:

I think researchers—beyond the content of their research and the findings, just simple methodologies and knowledge of protocols—can share a lot that would be useful for community agencies. It doesn't always have to be: here's the evidence. Basically, it can be more like, "Well, when you guys are doing your surveys, you should be asking these kinds of questions," or even things like, "Here's how to form a community IRB."

So there's something instructional, I think, that researchers can offer community folks. But then, secondarily, I think there is the issue of: well, what is it that needs to be researched, and what is that line of communication?

I actually met recently with a local researcher about lay health workers in the Asian community. She's been doing lay health worker research in the Hispanic community. And at the very end of the meeting, I said, "Well, when you get an idea about Asian health worker/lay health worker research, contact me."

And she looked at me, and she said, "No. You know what? You guys think through sort of what your research interests are, and give me a call." And that was a really interesting conversation to have.

Because I think it is a two-way street, in terms of: well, what research questions need to be answered? And which of those are relevant to people doing the work on the ground.

So I think the area of what research questions we are trying to answer is the other sort of key bit of information that needs to be sort of mutually shared between researchers and community-based folks.

Han:

I absolutely agree. So here's my question. I know you do have this one, but if you don't mind, please share with us some of the plans that you have to sustain your health program, which you described in the article.

Hirano:

Well, sustaining health programs is difficult, and I could probably talk for a half-hour about sustainability.

Because a lot of funders, nowadays, require you to put a section on sustainability in your grant proposals. So you know we're a non-profit that is about 95 percent grant funded and about 5 percent private donation/fundraising funded.

And one of the things that we, and a lot of agencies like us, need to do is to work harder on the private donation side, become less reliant on grants.

Because grants, in the end—even state grants—they'll give you money for four, maybe five years. But then they have to go back to bid, and there are procurement issues. And foundation grants sometimes will only—foundations will give you one, two years oftentimes. And after that, you're looking again, hat in hand.

So part of it is to do as we're trying to do—is to get better at grant writing and share the load and continue to do the opportunistic grant writing. And part of it, I think—and we're just talking about the funding part right now—is doing the due diligence, in terms of squeezing out private donations and doing the good fundraising.

Hirano:

From the programmatic side, it does come back to data and making sure that we're gathering the correct data to make our case, that if one grant runs out, we have good information from the program, and we can go to another funder and say, "This is the impact or effect we've had through our work."

Hopefully it's cost-effective or there's some type of return on investment. That's a whole 'nother issue—about the economics of what we do, which would probably make good research as well.

But in the end, we've done our homework. We've gathered the information we need on existing, successful programs to convince funders to continue to fund that kind of work.

Han:

Are there any additional thoughts that you'd like to share with us?

Hirano:

Well, there is some good news. I was at the American Public Health Association meeting in Washington earlier this week. And the federal government, I think through advocacy of national agencies, has agree to start oversampling Asian Americans and Pacific Islanders in some of their studies—their larger, nationally-based studies, like the NHANES study, which actually does clinical sampling—blood draws and other measurements.

Slowly, over time, I think Asians and Pacific Islanders have wanted to have their data gathered on a more granular level, at sub-ethnic group subgroups.

And that's slowly happening.

In fact, I think the Department of Health and Human Services just very recently, within the past couple of days, had also suggested that they will now start gathering data in a more granular way among Asian Americans and Pacific Islanders.

I think the entire area of research related to Asians and Pacific Islanders is slowly moving forward, both by individual researchers and by institutions that are willing to gather data that is more helpful to those of us on the ground.

So I'm really encouraged by that kind of activity. I think we can make great strides together over the next decade or so.

Han:

One of the comments that you made in your paper is this "less than one percent of studies" reference to Asian American and Pacific Islanders as a studied group in their literature. So with funding and collection of data about this API group, I think there will be a great chance for even better health in the community, who often experience all these health inequities and health problems as a group.

So it's been a pleasure talking to you and listening to your thoughts about all these different issues, and some of the additional insights about the programs, and your experiences. It's been a wonderful opportunity for me to learn more about the community activities that you've been doing, and I appreciate your time as well.

I hope that all our audience actually also shares my enthusiasm about this opportunity as well. Thank you so much.

Hirano:

Well, thank you for chatting with me.

