

Beyond the Manuscript: COVID-19's Impact on Community Resilience Practice: Lessons Learned from an Academic-Community-Government Partnership to Reduce HBV

Karen Mancera-Cuevas, Daisy Le, and Angeline Nguyen

Welcome to *Progress in Community Health Partnerships'* latest episode of our Beyond the Manuscript podcast. In each issue 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.

In this episode of Beyond the Manuscript, Associate Editor, Karen Mancera-Cuevas, interviews Daisy Le, one of the authors of, "COVID-19's Impact on Community Resilience Practice: Lessons Learned from an Academic-Community-Government Partnership to Reduce HBV" and her colleague, Angeline Nguyen from the Health Betterment Initiative.

K. Mancera-Cuevas: Welcome, everyone. We are speaking with Angeline Nguyen and Daisy Le. I want to thank you two for coming to join us today. Can the both of you give us a little bit of background about your professional experience before we delve into the conversation? And then, I'll introduce myself. Angeline, can we start with you?

Angeline Nguyen: Sure. So, my name's Angeline Nguyen. I work with the Health Betterment Initiative, or HBI, formerly known as Hepatitis B Initiative of D.C. I am a nurse and I manage the education and research study programs and I also do linkage to care for our positive patients. And I've been doing this for seven to eight years.

K. Mancera-Cuevas: Thank you. And Daisy?

Daisy Le: Thanks, Karen, and thanks for having us here today. I am Daisy Le and I am an associate professor at George Washington University in Washington, D.C. And I am a social scientist in behavioral community health. I specialize in community-engaged cancer prevention and health disparities research. And I am one of the coauthors on this manuscript and a lead on the evaluation team.

K. Mancera-Cuevas: Thank you so much for introducing yourselves. I am Karen Mancera-Cuevas. I am one of the associate editors for PCHP. And I'm excited to cover this topic today, critical particularly because it covered COVID-19, and so we're going to talk a little bit about that intersectionality, go through the questions, and really explore more of the manuscript.

To kick things off, Daisy, just to provide context for those of our readers that really want to learn more about what you described in the manuscript, can you provide more in-depth information on the development of the Washington-Baltimore Metropolitan Area Hepatitis B—WBHBV—academic-community partner–community-government partnership, including details about the partners and criteria for selection?

Yeah, absolutely. Our Washington-Baltimore HBV academic-community-government partnership—so, we’re going to call it ACG partnership for short—was born out of our need to tackle the hepatitis B situation in the D.C., Maryland, and Virginia geographic region. So, we call it the DMV region. And this is something that disproportionately affects a lot of immigrant communities, particularly people born in areas where there are high HBV prevalence—so, we’re talking Sub-Saharan Africa, East Asia, the Pacific Islands, even Eastern Europe. And so, essentially, individuals from these areas are at higher risk, especially if they’re not vaccinated at birth.

And so, the design of this partnership—so, I did want to say this project was under the leadership of Dr. Yang, who was the principal investigator for this originally funded project by the Office of Minority Health. It was a demonstration grant, so it’s meant to actually get services into the community. And the design was very deliberate. It was meant to be a multisector collaboration that included—we had our community organizations, we had local health departments involved, and then, of course our academic institution, which is the George Washington University.

When we kind of think of how our partners were selected, and I’m going to start with the CBO side, the core criterion that the PI had in mind was making sure that we identified stakeholders who were already deeply embedded within the immigrant and higher risk for HBV population. So, the CBOs, for instance, had to have a proven record of delivering culturally competent care, particularly within, for example, the Asian and African immigrant populations, because we know that these groups have been shown to have higher risk of chronic hepatitis B in our area.

It’s also important that these organizations were not only trusted within their communities but that we could—that they themselves could also help us mobilize outreach and educational efforts in ways that would be—that would resonate culturally and linguistically within the populations that they serve and come from. One of the CBOs that—in the ACG partnership is Health Betterment Initiative of D.C., which Angeline represents today. And this is just one example of a CBO that has been conducting free hepatitis B screening, vaccination awareness campaigns for years. In fact, I worked with this organization years before this project even came along, so it was very interesting to see kind of this wraparound of how we could collaborate again on a similar topic, years later in a different aspect.

And so, besides the CBOs, we also had public health departments pulled in and we had the D.C. Department of Health, and Maryland, and that’s because we—because of their capacity to help provide resources like vaccines and data infrastructure and also of course their general public health expertise.

From the academic side, we have GW; to pull in the funding to make sure these services could be implemented, but also to eventually be evaluated to see how we can keep it sustained. And so, for us, from the academic side we kind of were—we were meant to bring the research and evaluation expertise. That’s how I was pulled into this project. And this expertise was essentially needed to kind of help us systemically assess the program or the work that was already being done, I think, to kind of assess the impact and then to kind of make adjustments along the way.

So, it was very crucial to have this entity among the—to have the academic team as part of this partnership because we needed to also come from using rigorous framework to kind of see—to guide the program, to make sure that we’re actually using models that could be replicated in other areas that could essentially be grappling with similar health disparities that we’re dealing with in the DMV region. So, I don’t—I think this partnership, between community, academic, and health departments, it’s nothing new. It’s something that has been mirrored, that we’ve seen in the literature that has been

implemented across different parts of the nation. But we wanted to make sure that we were kind of getting our community activated for this particular topic in our particular region and to kind of see what works for us and what didn't.

And so, the whole point was to bring us all to the table, to make sure the decision-making process was consistent across the board, that all voices were being brought to the table from the start, from end to end.

K. Mancera-Cuevas: I really like how you just mentioned about having the prior relationship with Angeline and the organization. Does that really help make future partnerships much more seamless, compatible with expectations as you're going into the relationship? Can you speak to that?

Daisy Le: Yes. Definitely. So, for me, absolutely. So, I'm—when I was brought on, the grant had already been written, awarded to Dr. Yang. And so, when then I'm being told of what I'm tasked to do down the line—I was brought on to do the evaluation a little later on—I was like “Oh, my God. These are organizations I worked with.” It made it very—almost seamless for me because I've already worked—I work a lot with the community and a lot of the CBOs, and so it was easy to kind of—of course the turnover of staff, of course, there's going to be turnover and it's not going to be the staff across the projects that I worked with before, but at least two of the three evaluators, which we'll probably talk about later, we've actually had these relationships with HBIDC. So, it was great to kind of really push them to talk more about all the work, their history, their work, what they—what has changed. It was—for me, it was really nice to see how they've grown in the years. I mean, they—just even the name change, Angeline will probably talk about that, but the name change alone, you'll understand how much they've just grown and expanded in the past—from the past since I've met them.

K. Mancera-Cuevas: And Angeline, can you expand on that in terms of having that prior relationship and then coming into this new partnership? Your thoughts on that?

Angeline Nguyen: Well, I worked under our executive—former executive director, Jane Pan. So, she's the fact of everything and all the work that we've done, she'll be like “Oh, well, we need data. We need you guys to do this for GW or other partnerships and organizations.” So, every time she tells us that we're going to be working, we're like “Oh, that's fine. We've worked with them before. We've shared our work.” And it just—the partnership kind of highlights our work behind the scenes, and then Daisy and the academic organizations kind of bring everything to life with the numbers, the rates that we might not notice, but we do the ground work, we do the phone calls, we do the outreach, the education. And it's just nice that—because we're kind of grass roots. When I first started we only did events on the weekends. And then, we slowly expanded. We were able to start doing point of—the point of—I don't know what it's called—point of contact screening. We brought the screening to the members of the community where they worked so that they didn't have to leave work to get the screening. So, we slowly expanded.

And now, because we didn't want to just focus on hepatitis B, our new CEO, Sandra Ashford, thought that we should rebrand to Health Betterment Initiative because we want to focus on overall health. So, we not only do infectious diseases like hepatitis B and C and HIV but we're also wanting to do education on prevention—so, overall health. So, we've definitely expanded from just hepatitis B, but it's still very important work because we still work with the underserved communities and we want to make sure that everyone has equal standing, equal treatment, a linkage to care, everything.

K. Mancera-Cuevas:

All right. Well, thank you so much. So, let's move on to a couple of other questions, including, Daisy, can you speak to the external evaluation team and their expertise just so readers can get a better background on that layer of information and that experience?

Daisy Le:

Yeah, definitely. And so, our external evaluation team is a team of three for this particular manuscript. And so, we were brought on—two of us represent George Washington University and then another one from Thomas Jefferson University, who actually was originally at Johns Hopkins. I worked with her before. She worked with HBIDC as well, separately on her projects, also on this topic.

And so, we were pulled together based on our expertise in mixed method, but at least two of us were very strong in qualitative research method and the third individual was very strong in quantitative research methods. And we were particularly valuable for this project because of not just our methodological expertise—so, qualitative/quantitative—but also because all three of us have—our work is integrated into community. So, all three of us have—in our personal individual research projects, we have worked in the community, across numerous aspects. So, it's not just HBV. So, I—a lot of my work is in women's health, so the human papillomavirus and cervical cancer.

And so, we were brought on to represent methodological expertise but also communities that we serve. So, two of us have, for example, worked very intimately with the AAPI population. The third individual has worked very closely with the DMV area of African immigrant population, for example. So, we kind of represented the different aspects that the project was supposed to try to reach, and to really understand the people working with the community and then where they were coming from.

Our—I guess, yeah, so we just kind of represented that. And the whole point of having an external evaluation team was oftentimes if you're already part of the team, you're biased in your perspective of how you see things and what you might recommend. So, we were specifically not supposed to be a part of any of the data collection. We took what they were already doing and we're trying to document it. We're trying to see—like what Angeline was saying, they do all this great work. And everyone across that DMV region is doing this great work, but how can we bring them together and then activate this coalition. And so, that's what we were attempting to do under Dr. Yang.

So, we documented, we collected data from them. They would report their quantitative data to us—how many people they've screened, how many were linked to care, et cetera—and then, what we did was added this qualitative component where we interviewed key staff members on that coalition, about their work. This was to help us kind of understand what was working, what wasn't. So, aside from the numbers, the stories behind the actual work was what we were trying to achieve.

K. Mancera-Cuevas:

Thank you. Thank you. So, that gives a bit more information in terms of that experience. Angeline, so I'd like to explore how the COVID-19 pandemic impacted the HPV programs. There was a lot of description in the manuscript but I would really like to know what your thoughts are on pivots required for program sustainability. We saw what COVID brought. But I wanted to know your thoughts. And in addition to that, are there strengths, challenges that come to mind? And how do you address this with community members? So, bring that all to fruition. What are your thoughts on that?

Angeline Nguyen:

So, definitely when the COVID-19 hit and everything was shutting down, as a community-based organization we panicked a little bit. We were like "Oh, no, we can't do what our strengths was," which was in-person outreach, education, and screening. So, Jane brainstormed. She thinks big. She thinks outside the box. So, what we had in our, I guess, arsenal was we did have a small hybrid process where an individual could register on our website and a staff member would get this registration form,

kind of assess the client's needs, call them, talk to them, like their risks and everything. And then, "Do you have insurance?" If you have insurance, we'd connect them to a doctor. They can get screened through that avenue. But most likely, they don't have insurance. So, what do we do?

We are able to help them schedule an appointment at LabCorp, or any labs, and then get tested where we get the results. We'll call them, go through their lab results with them, and then link them to care if they're positive. So, we had a couple of organizations that took clients without insurance, especially hepatitis B. So, we only utilized that for our clients who couldn't come out to events because of limited scheduling. They worked on the weekends; they couldn't come out to our weekend events. So, Jane said, "Okay, we will put this link everywhere, all over social media. If you need to get screened, click this link and we will get back to you." So, that's how we slowly started using our hybrid process.

We also partnered with local culturally competent doctors who were familiar with hep B. We had CHWs who also worked in those locations where people who were at risk, people who have never been screened for hep B before, she would order the labs and then we would get the results and then the doctor was already there. They would discuss the results and they were already linked to care. So, we also had that avenue.

So, we definitely used our hybrid process, definitely used social media. And challenges? Definitely linkage to care. Everywhere they were like "We're not open right now." So, a lot of our clients, when we called just to follow up with them and not only offer them resources and stuff but we were finding that unemployment was a big, big problem. They were losing their jobs because everything was closed. That means no insurance. No insurance means "I'm not going to the doctor. I can't afford to pay for treatment" because they have to meet the needs of their families first: food, shelter, all that stuff. So, we called all our hepatitis B patients. We gave them education on infection prevention with COVID. But we also say, "Hey, what are you doing for your hepatitis B? Are you going to the doctor's? Do you need help? What kind of barriers? Do you have transportation barriers? Insurance barriers? What?" And then, we would address it with them.

We had a CHW, one of our community health workers, she's Mongolian so she helped facilitate linkage to care with our Mongolian hepatitis B-positive clients. They—the patients admitted "I've just been busy trying to find work. I have not been going to the doctor's. I haven't been taking medications. I never picked up my prescription." So, she's like "Okay, what can we do?"

So, she got on the phone. It was a three-way call with the health care provider. The clients didn't know that their telehealth was an option. So, she helped them make an appointment with telehealth. They didn't know that they could just call just for a refill for their medication. The client thought they would have to go to the doctor's office, make an appointment, go see the doctor just to get a refill. But because of COVID the providers were willing to give another month's refill until they came in or had a telehealth visit. So, we also utilized that kind of method through telehealth to help our clients get continuity of care and treatment.

Other challenges? Because COVID was kind of the forefront of every health care education, a lot of hep B outreach got kind of put on the back burner. But we kind of saw "How can we put this together? How can we solve everything?" So, yes, we called our clients about COVID but then we also gave—reminded them, gave them education on "Yes, hepatitis B doesn't have symptoms that you can feel or see right away but we don't want you to get there where you see symptoms. So, when you go and see your doctor, talk about COVID but then you need to really talk to your doctor about what else you can do if you don't need medication to prevent liver damage and things like that."

And then, once COVID vaccines came out we also paired that with “Okay, well, you know what? Your test results show that you’re also not immune to hep B, so when you go get your COVID vaccination go ahead and get your COVID—your hepatitis B vaccinations as well.”

So, yes, we had to use creative ways. We had to be flexible for our clients as well. And we utilized virtual and telehealth to help incorporate all—everything from education—we had webinars, free webinars that people could sign on where local doctors could talk about hepatitis B. And outreach, we used social media—Facebook, Instagram, Twitter—to help provide education as well as our hybrid program.

K. Mancera-Cuevas:

Thank you, Angeline. And I particularly thought that it was interesting how you were working countercurrent with hepatitis B and then COVID. For many of us that were in the space, it was challenging because you’re still trying to make sure that the patients are keeping front and center with hepatitis B while at the same time being conscious of COVID and seeking treatment simultaneously even though there’s a lot of restrictions. And so, that layering makes it challenging, then, for patients, then, to engage in those health-protective behaviors.

Angeline Nguyen:

Right. And there was a lot of fear about going out even to the doctor’s office. They were like “Well, no, I’m going to get sick if I go there.” We’re like “Well, if anything, you probably wouldn’t get sick because they’re more safety-conscious.” But we had to provide education, a lot of—to help lessen the fear and the stigma, not only with hepatitis B but now with COVID as well. So, yes, that was definitely a big barrier in getting clients to go to their appointments.

K. Mancera-Cuevas:

And definitely a tie-in to the next question that I have for the both of you. So, you just mentioned, Angeline, the role of telemedicine/telehealth. There were challenges and opportunities that were unique. But can you describe implications for future practice with similar communities? I know that this was very unusual, had to pivot under COVID, but lessons learned, do you think that there are lessons learned that can be applied for the future?

Angeline Nguyen:

I think so. A lot of our clients, they use their phones. They might not have a computer but they always have phones. And they have their apps, like WhatsApp or WeChat or whatever. So, we actually utilize that to help us spread the word about COVID prevention and hepatitis. So, I know one of our CHWs had to help someone navigate telehealth, but once they got over the fear of using their phones for this they were like—they didn’t have to worry about transportation and the barriers, because I think this might have been a more elderly client who didn’t drive, so she had to rely on other family members or friends to drive her to appointments. So, that was why she couldn’t get to her appointments or why she couldn’t get her medications. But once she was introduced that “You can use your phone to help you with your health care needs,” it kind of opened a door for a lot of these clients who thought that they weren’t going to be able to see their doctors.

And also, I think with telehealth there’s a translator/interpreter option. So, now with language barriers that also helped alleviate some of that factors as well. So, our Mongolian interpreter, she also utilized that by getting permission from the client to help translate or interpret during an appointment or help schedule appointments as well.

Daisy Le:

Yeah, I think Angeline definitely gave some great recommendations of what we’ve learned from this project and based on their work. Those challenges were definitely—one of the major ones that

became a learning opportunity for everyone during COVID was the technological literacy, or the lack [of], and also the need for that platform to be culturally and linguistically appropriate. So, it's one thing—we all had to just jump because it was COVID. So, I think that was interesting for some to just even understand the telehealth aspect, like Angeline said. Having to use a phone to actually get on to—appropriately, because then there's different medical servers and platforms for them to jump onto. Some require us to do the audio and video check before they even get to see the doctor. Some require being in a waiting room.

And so, it's gotten a lot more advanced but that also causes a lot of challenges for a lot of the communities we work with, which are immigrant population, older population, who are—for some of—even my parents, they are barely just knowing how to talk on the phone and maybe occasionally text “Okay.” So, it is a challenge even though many of us are used to this telehealth because it's been a couple years of it. So, I think that's a lesson learned. It's like making sure we still have basic workshops on how to use these platforms, how to best access them, how to understand how to appropriately communicate with the provider on them. And then, like Angeline said, making sure that we have the linguists, the translators on—available if we know that they're going to be someone that's going to struggle with the linguistic barrier with the provider, because we don't want them to just—they can see the provider because of the telehealth, the video capability, but then not be able to communicate, truly communicate what they're feeling or what they're—or what they mean. So, I think that's definitely a lesson learned. It's great, we're on telehealth, we see you, but how do we continue to break down those other barriers that were there even during in-person visits, like a translator—having the translator.

And I think one of the major things for me coming out of all of this and COVID in general is the broader implication for us to integrate telehealth with in-person care. So, I think coming out of it—so, a lot of places are now offering hybrid care. So, kind of figuring out what that balance looks like for the different communities we work with, and serve. So, we use that word “hybrid” a lot of times, at least in my work, but that differs so much based on the CBOs you're working with or the hospital you're working with and the person you're working with. And so, I think really kind of think of what do we mean by “hybrid” and are we truly thinking of what's best for the patient population that they primarily serve.

So, kind of blending the two, because yes, it was convenient to be on telehealth but I know some of the participants, study participants I actually work with, they still say that they actually prefer in-person interaction, especially since COVID. They want that interaction, that warmth of just being in a room and just having the doctor's attention. Telehealth is supposed to be that too, they're supposed to feel that, but I've had patients that have said they don't feel that on a telehealth visit.

And then, it's not a one-size-fits-all. Telehealth is—everyone says it's telehealth; telehealth is the future. But it's not a one-size-fits-all. It had to be. Let's be honest; it had to be because COVID came at us real fast and we all had to transition. But I think—Angeline knows this very well—that it ranges based on the people we serve. And we do have to figure out how to make it accessible to everyone because not everyone—like Angeline said, not everyone has a computer and some of these platforms still require that. Not everyone has—during traditional office visits, the telehealth office, they might have to be at the library but that's not private. And the provider has to—I have had patients turned away because they weren't in a private setting, for obvious reasons. But that is a concern because—but that was the only way that they could see their doctor. Really thinking about that, regardless of whether

they're tech-savvy or not, the language proficiency, or socioeconomic status, I think we really do have to consider all of those when we think about telehealth being a one-size-fits-all because it can't be.

K. Mancera-Cuevas: Well, thank you so much, Angeline and Daisy, for your insights and to provide us more information, background on the ACG partnership. And thank you for sharing the lessons learned and opportunities with engagement with all of your partners described. That is pretty much it.

Angeline Nguyen: Well, thank you for having us.

Daisy Le: It's been great. Thank you.

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