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Podcast Interview Transcript

Alana Lebron, Cindy Gamboa, Suzanne Grieb

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.

Suzanne Grieb: My name is Suzanne Grieb. I'm a research fellow at the Center for Child and Community Health Research at the Johns Hopkins School and Medicine and I'm an associate editor with the journal.

Today we will be discussing your paper *Storytelling and Community Intervention Research: Lessons Learned from the Walk Your Heart to Health Intervention* published in the *Works in Progress* in Lessons Learned section of the journal. So welcome. Could you please both introduce yourselves?

Alana Lebron: Sure so this is Alana. My name is Alana Lebron and I'm a doctoral candidate at the University of Michigan School of Public Health in the Health Behavior and Health Education Department. And my research focuses on social, socioeconomic, racial and ethnic inequities in health. And as part of my training, I've been working with the Healthy Environments Partnership to kind of better understand the contribution of social and _____ environments to racial, ethnic and socioeconomic health inequities with a particular focus on factors that affect the health of Latinos.

Cindy Gamboa: Hi, this is Cindy. My name is Cindy Gamboa and I'm the project coordinator for the Healthy Environments Partnership, which is a community-based participatory research project in Detroit that focuses on understanding the cardiovascular disease inequalities that are happening in our city. And I'm also a resident in Southwest Detroit.

Suzanne Grieb: Cindy, would you please orient our listeners? Or to orient our listeners, would you please provide us with a brief summary of the project, both the overall Walk Your Heart to Health intervention as well as the storytelling component described in the manuscript?

Alana Lebron: Sure so this is Alana. What we thought was – perhaps I'll just provide a brief overview of the project and Cindy can provide some more detail.

So the Healthy Environments Partnership or HEP, as Cindy mentioned, is a community-based participatory research partnership. And this partnership really consists of community-based organizations, representatives from health services and academic institutions. And it began in 2000 with the goal of understanding and addressing features of the social and physical environment that contribute to the patterning of cardiovascular disease risks for residents in three neighborhoods of Detroit that have the greatest risk of disease.

Alana Lebron:

And so early on in the partnership, HEP engaged community residents in focus group discussions and town hall dialogs to identify factors that residents prioritized in addressing these factors as they relate to cardiovascular disease and to really help identify opportunities for intervention to reduce these inequities. So through this process, HEP's steering committee identified addressing physical activity through walking groups as a promising intervention strategy. And the intervention is called Walk Your Heart to Health Walking Group Intervention, which was designed jointly by community health service and academic partners in the Healthy Environments Partnership with a lot of community input along the way. And this walking group intervention was really part of a multilevel intervention to improve physical activity. So the intervention began in 2008 and completed in 2013.

Cindy Gamboa:

Hi, this is Cindy and I just would like to add that over the course of the intervention, the project staff provided regular reports about the walking group to the steering committee and identified that participants in the walking group tended to drop off a little bit after the first eight weeks of the intervention. The project staff, including the community health promoters that led the walking group who were also members of the communities where the walking groups were held, identified social support and other barriers to physical activity as being the main factors that contributed to the challenges in maintaining the improvements in physical activity for the participants.

So the steering committee really started to discuss the challenges and formed a subcommittee based on input from community and academic partners to review the research and identify suggested intervention strategies for a sort of enhanced maintenance intervention. The subcommittee identified two major themes, two intervention themes, that enhanced walking group participation during the maintenance period of the intervention. And those were identified as building social support for walking and problem-solving.

Suzanne Grieb:

Great and so that will provide our listeners some background about the project so thank you. And your partnership, the Healthy Environment Partnership, can you share with us a little bit how it was started?

Alana Lebron:

Sure so the Healthy Environments Partnership is a community-based participatory research partnership that is supported by the Urban Academic Research Center at the University of Michigan. And there's long been an understanding about cardiovascular disease inequities that are experienced both when comparing the health of Detroit residents to the health of residents in communities right outside of Detroit and to residents of Michigan and to the broader national population. So this work really emerged from some of the work of the Urban Research Center and persistent inequities in cardiovascular disease risk.

Cindy Gamboa:

Hi, this is Cindy and I would just like to add that HEP is really committed to learning about factors that contribute to cardiovascular disease inequities for residents in the city of Detroit. So the community has different resources that – or different factors or opportunities to support this work. So HEP is invested in building capacity amongst the steering community members, so these partnership activities and processes are helpful for developing skills within the partnership. HEP also works to ensure that everyone who needs to be at the table perhaps as members of the steering committee or working with HEP on particular projects are represented.

- Suzanne Grieb:* And how is that decided who is not at the table and who needs to be asked to join?
- Cindy Gamboa:* So, for example, as HEP started disseminating the walking group intervention and continues to evaluate the walking group intervention, the steering committee may identify other members or organizations that it would be useful to collaborate that are working with physical activity efforts in the city.
- Suzanne Grieb:* Okay, good and in the manuscript the authors mention that between 2005 and 2008 the partnership members went through a planning process to identify and pilot strategies to reduce cardiovascular disease inequalities. Alana, can you share what this entailed, what the community and academic partners brought to this process where any conflicts in this process were handled and how the final intervention was identified as the one to move forward with?
- Alana Lebron:* Sure, I can begin to speak to that so this is Alana. And, right, so from 2005 to 2008 the partnership really drew on information that was raised during focus group discussions and town hall dialogs, and residents really provided some rich information about what they saw as features of their neighborhoods and communities that really contributed to the concentration of cardiovascular disease in their neighborhoods. And they identified a lot of issues, right, so we know that cardiovascular disease may be affected by dietary practices and availability of healthful foods as well as physical activity practices in all the structural factors that go into physical activity. Others identified kind of larger features of the context in which they live that contribute to major stressors in their lives.
- And so the partnership really assessed what was also happening locally within Detroit and identified that there's a lot of great work really going on to assess the food environment but that there was a real opportunity, too, to really intervene to improve physical activity while also noting that it's not just about getting people out and engaging in physical activity, but there are major kind of structures that prevent access to physical activity. So the partnership really identified the need for building support for physical activity and also recognizing the need for structural support of that so doing things like ensuring that pathways are safe and accessible.
- Suzanne Grieb:* Okay and how did storytelling come in as a component of the intervention?
- Alana Lebron:* So this is Alana so the Walk Your Heart to Health intervention, the core intervention, began with the intention of developing and establishing the walking groups. And several of the community health promoters and other staff that worked on the intervention more directly really recognized that participants were very actively engaged in the intervention during the first eight weeks of the intervention but that they really sometimes began to drop off after that. And through their kind of more intimate work with the walking groups, the HEP staff identified social support and problem-solving as major challenges, specifically that the participants were often encountering challenges to attending the walking groups and walking on their own outside of these walking groups. And so the walking group staff brought that information to the steering committee, and the steering committee discussed ways in which HEP might go about addressing the intervention to better support and promote walking groups. Cindy, do you want to say more about the storytelling aspect and how that came to be?
- Cindy Gamboa:* Yeah so I'll discuss just an example of ways that we adapted to the context of each one of the walking groups if it's okay. So one of the things that we did was to try to adapt to the context of each one of the walking groups.

Cindy Gamboa:

One example is that we told a story when we were building on the theme of building social support for walking. We used the story Marsha Brown's *Stone Soup*. In the story a boy who is hungry meets a woman and she allows him to make stone soup in her kitchen using only water and stones that he picked up during his travels. In the story he convinces several town members to come together and prepare the soup. Each brought a different ingredient from the soup. And at the end of the story what begins with water and just stones turns into a delicious soup that's made and shared by all town members, right?

Now the story conveys the theme of reaching out, giving back and finding balance for kind of lifelong health, and it's kind of emphasis on building social support amongst people in a community. And one thing as a resident of one of the predominantly Latino neighborhoods in which several of our walking groups were located, I knew intimately that the original – just the stone soup ingredients wouldn't resonate with the predominantly Latino walking group participants, and I was really concerned with the message that would be lost in the story if it didn't resonate with the participants. So I suggested that we alter the ingredients of the soup to reflect those that are more likely to be familiar with the participants at each side of town.

And just from our experiences it provides an example of how HEP's participatory process in developing an intervention that was sensitive to the context in which walking groups and the participants were embedded was really helpful. These understandings informed the selection of storytelling as a strategy to deliberate intervention themes allowing the stories to be adapted across the walking group sites.

Alana Lebron:

This is Alana so to answer the question of why storytelling, so after the Walk Your Heart to Health staff brought their findings to the steering committee, the steering committee then selected a subcommittee to really look at the public health literature about interventions addressing social support and building problem-solving skills because they wanted to see if they could kind of add that component to the intervention during that kind of latter phase where people were really starting to drop off.

And the subcommittee did identify kind of several effective strategies, but one challenge that we know that kind of faces these health behavior and health education interventions is sometimes that they can be very didactic, right. And so based on the evidence in the literature as well as the experiences that the walking group staff were sharing with the HEP steering committee, the subcommittee really worked to identify a way that would be effective to engage participants in a discussion, a kind of thoughtful and critical discussion about factors that are barriers to walking and to participating in these walking groups. And storytelling was really identified as an effective strategy to engage, people, right. It's a very common way of conveying narratives for particular populations and kind of broader kind of historical narratives and really getting people to engage with some of the thoughts. So that's a little bit of the background as to why storytelling was the mechanism by which we kind of delivered this enhanced maintenance intervention.

Suzanne Grieb:

Okay, great and, Cindy, you mentioned – you gave a great example of how the stories selected were altered to make them culturally relevant. And in general because the project included both African-American and Latino community members, how did the partnership acknowledge and work through some of the issues around cultural competence and cultural sensitivity.

Cindy Gamboa:

The benefits of having the community-based participatory research project is that we were able to engage community members from these very diverse communities. A lot of the members that were on the steering committee were from the communities where they serviced or have been there for a very long time. So they have that intimate either relationships with them or really that cultural understanding of the people that they work with every day. So every time we would come together and talk about these different challenges that we were experiencing during the intervention, they could talk about the different strategies that might be more useful based on the populations that they serve.

Suzanne Grieb:

Okay and in what ways outside of these issues did the partner members' different disciplines and backgrounds enhance this overall project?

Alana Lebron:

The different backgrounds and histories and skills and disciplines are really a real strength for HEP steering, right. So the steering committee includes service providers, health service providers and academic partners as well as two community members at large. And they all bring with them their intimate knowledge of how the social and physical environments in Detroit unfold in their particular neighborhoods and in the communities that they serve as well as how this environment is changing or not as this partnership has evolved and advanced.

So I think another kind of unique contribution of the steering committee is the librarian that was then engaged at storytelling was identified as the kind of intervention mechanism for this enhanced maintenance intervention. She was part of some policy advocacy trainings so she's a real asset to developing the storytelling intervention, and the steering committee really knew her through a lot of activism that other steering committee members are engaged in.

Suzanne Grieb:

Okay and so thinking about the partnership and the intervention selected, what can you describe or can you describe your project's successes and challenges in designing and implementing this program, particularly around maybe the partnership dynamic and process?

Alana Lebron:

Sure so, as we mentioned, the partnership really initially discussed factors that contributed to this dropoff in participation in walking after the first eight weeks of the intervention and identified forming a subcommittee to kind of more intimately explore ways in which they could enhance the intervention.

So throughout the process of the subcommittee looking at the literature, discussing what the literature shows as far as intervention strategies to build social support and problem-solving skills, the subcommittee kind of throughout the process brought their findings back to the larger steering committee for feedback and then would kind of return and address the issues that were identified in the larger steering committees meetings during those subcommittee meetings. So once they'd kind of identified some themes to the interventions like reaching out and giving back to build social support, they then focused their energies and efforts on identifying a way in which to convey these intervention themes, brainstormed and brought those themes back to the steering committee.

With respect to kind of success and challenges, HEP's framework really understands that individuals are embedded in these very complex systems, right, these very complex and interconnected networks. And so really we understand that factors that influence walking group participation and walking in general are contextually driven and that sometimes there are these contextual differences across sites and that there may be a need to tailor some aspects of the intervention to those sites.

Alana Lebron:

So I think that the example that Cindy gave was really indicative of kind of HEP's acknowledgement that there is this race-based residential segregation in Detroit, and that means that these three priority neighborhoods that the population and participants that are engaging in these walking groups may differ across sites and there may be interconnections between the social and physical barriers to engaging in physical activity that they encounter and they may also look different. And so storytelling and the format of the intervention really allowed for there to be this enhanced maintenance intervention that resonated across groups but that was allowed to really also be tailored to the context that participants were confronting. And the steering committee was really critical to helping the walking group intervention staff to acknowledge and address some of these contextual factors.

Suzanne Grieb:

And so what were some of the challenges in this process?

Alana Lebron:

The challenges. So one challenge was that we mentioned in the paper there were two intervention arms for this enhanced maintenance intervention so one was social support intervention arm and the other was a problem-solving intervention arm. So there's some challenges in the logistics of doing that and ensuring that these interventions are distinct and don't kind of overlap and feed into each other.

Another challenge that was raised was with respect to the storytelling activity, and we discussed this a little bit in the paper. But the real intent of the walking groups was to get people walking and to do so in this kind of very supportive environment. And so the storytelling intervention was designed to just be a couple of minutes of storytelling and then to encourage participants to discuss the themes as they were walking. Cindy, do you want to talk about the challenges that unfolded though?

Cindy Gamboa:

Yeah, I can say just as being one of the stand-in storytellers, the stories actually took a lot longer than just a regular five to ten minutes that we had hoped they would be just to set the stage. A lot of people became really engaged with the stories and really had the chance to start dialog amongst each other. And I think some of the stories really resonated with them and they internalized it and had sometimes lengthy conversations about what that means to them and in their individual health.

Suzanne Grieb:

And you mention in the paper that the additional sessions, the maintenance arms or the two intervention arms, the enhanced ones were funded through additional funding. Could you elaborate on who funded that and how the partnership was able to get that additional funding for those additional arms?

Alana Lebron:

Sure so this work was funded through a comparative effectiveness focus of an NIMHD grant. The walking group staff and the HEP steering committee had already discussed the challenges that they were really seeing in the walking groups with respect to maintaining participation in the intervention. So they had already engaged in conversations about an interest in identifying an enhanced maintenance intervention, and this CER or comparative effectiveness research grant came up. And HEP decided to apply for those funds that it would be very well times to support an opportunity to really think through and implement an enhanced maintenance intervention.

So comparative effectiveness research, the essence of it is that we really need to move beyond just comparing an intervention group to a placebo control group to really moving to comparing what works best at the moment to something that's added and enhanced so kind of removing that placebo comparison group and identifying what's added with this intervention that's being tested.

And so what we sought to do was compare the processes and outcomes from these enhanced maintenance interventions to this core intervention, which we now have evidence that was effective in

improving physical activity and also with reducing risk factors for cardiovascular disease. But the question here was if we built support for walking during this latter portion of the intervention, what would that look like? And we identified social support and problem-solving as two strategies that we could really work on developing amongst participants. But we didn't know kind of which would work best and so that was the comparative element in that we were comparing the enhanced maintenance problem-solving intervention to the enhanced maintenance social support intervention to the core intervention.

Suzanne Grieb: Okay and what are the next steps being taken with this project?

Cindy Gamboa: This is Cindy so HEP right now is currently focused on building the walking movement in Detroit. So based on the evidence from the walking groups that show that there is a reduction in cardiovascular risk, we want to go ahead and take it to the next level and disseminate it in our neighborhoods, in our Detroit neighborhoods. So as part of this effort, HEP is implementing a capacity building program so this is offered to faith-based and community-based organizations that are interested in starting and sustaining their own walking groups. So this will give residents more opportunities to attend walking groups throughout the city.

We're also offering opportunities for members in the community to take part in trainings and technical assistance that HEP is still offering for members that want to start their own walking groups. So one example I can share is what we call SWAG training. It's supporting walking groups, stands for supporting walking groups. And this training is offered to just citywide to all residents that are interested in starting a walking group. It consists of multiple workshops totaling up to 12 hours and we go through a lot of different topics such as group facilitation, route setting, building rapport with walkers, things of that sort. But we are also still working heavily with community-based and faith-based organizations through this capacity building to really help them sustain their walking groups throughout a longer term.

Alana Lebron: And this is Alana. The other thing that we're doing right now is we're turning to the evaluation of the comparative effectiveness intervention. So we're looking at differences in participation, number of steps walked and other outcomes for those who only receive the core intervention, those who receive the enhanced maintenance interaction either the social support arm or the problem-solving arm.

Suzanne Grieb: Great and the continuation, the trainings that were mentioned, is this funded by the CER grant or was additional funding sought for this effort?

Cindy Gamboa: Yeah, this is additional funding that was sought. It's just a dissemination grant from the previous intervention, the Walk Your Heart to Health intervention.

Suzanne Grieb: Okay, great and well, thank you both so much for talking to us. You both provided great insights into the project beyond that in the manuscript. Is there anything else that you would like to tell our listeners about the project or anything else before we close?

Alana Lebron: I think we could close by just noting that we have found the walking groups to contribute to a reduction in cardiovascular disease risk. And so HEP is now turning its attention to finding ways to kind of institutionalize support for walking. So there remains work to be done but it's very exciting to see that this intervention has been successful and to find ways to disseminate it more broadly both in Detroit and in other communities.