

Podcast Interview Transcript

Shannah Tharp-Gilliam, Michael Yonas, and Simona Kwon

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

In this episode of Beyond the Manuscript, Associate Editor Simona Kwon interviews Shannah Tharp-Gilliam and Michael Yonas, authors of "Using Concept Mapping to Explore and Engage Parent and Youth Residents of an Economically Underserved Minority Community around Children's Asthma."

Simona Kwon:

Dr. Shannah Tharp-Gilliam and Dr. Michael Yonas, thank you for taking time out of your busy schedules to talk with us on Beyond the Manuscript. I'm going to be asking the both of you a few questions and it would be great if you could introduce yourselves, your organization and title as you respond to the questions. So my first question is about the organizations and your academic community partnership.

Can you please describe the partnership that formed Healthy Living, Healthy Learning, Healthy Lives? And it would be great to learn specifically how long you and your organizations have partnered and if there are additional health topics that you collectively have worked on besides and building on the asthma project that you wrote about in your article.

Shannah Tharp-Gilliam:

Sure. Thank you very much for having us. First of all I would love to acknowledge our co-PIs on this project. Along with Michael and myself we have Anita Zuberi, Anna Kasunic, Patricia Bamwine, Stephanie Boddie and John Wallace. So you ask how did our partnership form. This was one of the more natural partnerships because our organizations and the university have been working together for quite a while. In fact I represent the Homewood Children's Village. I'm the director of research and evaluation, and I've been at the Village for almost six years now. Dr. Wallace from the University of Pittsburgh was the founder of the Village. So this project was predicated on the relationship that started at the very beginning of our organization. And over time the University of Pittsburgh's School of Social work, the School of Medicine, began to rally around the work that we were doing at the Homewood Children's Village. So when the opportunity arose to partner on this project we were already familiar with each other, we had built trust with each other, and we were ready to move forward.

Michael Yonas:

Yeah. Thank you, Shannah and thank you Simona for having us. This is Michael Yonas. I'm currently a senior program officer for research and special initiatives at the Pittsburgh Foundation. I still remain close with the Homewood Children's Village and at the time was serving as one of the co-academic PIs for the initiative and as Shannah mentioned, this had been built upon years' worth of collaboration.

And I was introduced because of some of the work that I was doing related to asthma, social and environmental stressors using participatory research elsewhere in Pittsburgh. But it was clear that a strong relationship had been really well established both academic and community and then also involving many organizations within the Homewood community. And probably five maybe even eight years of I think previous work that have gone on in that space.

Simona Kwon:

Thank you so much for sharing that background. I know a lot of our readers are always interested in understanding the nature of the partnerships and how long the groups have worked together.

My next question is focused on the topic of childhood asthma. How did HL-3 decide to focus on childhood asthma as a community health topic? One of the things that I thought was really interesting in your article is that you noted that one of the main data points that drove the study was the rate of school absenteeism among the youth affected with asthma. And I was wondering how did that data point come up and how did the focus on asthma come around?

Shannah Tharp-Gilliam:

That's a really good question. The Homewood Children's Village is a place based initiative focused here in Homewood, which is a neighborhood on the east side of Pittsburgh. It's an urban environment with high rates of crime and poverty and unemployment. And the work of the Village is to use education and academic achievement as levers out of poverty and into sustainability and families that can support themselves.

Our work focuses on academics, and we think a lot about what are the key levers. What are the barriers that support or prevent youth from graduating from high school and moving on to post-secondary opportunities? And what we noticed looking at our data was that the schools that we serve have the highest absenteeism rates in the district.

In fact the high school with which we were working had a rate of chronic absenteeism—meaning that kids were missing more than 10 percent of the days of school each year—their rate was 53 percent, which is amazingly high particularly—actually, it's 58 percent—correction there—58 percent, which is, you know, really high, particularly when you look at the context of the rest of the district which was 31 percent.

So with that in mind Homewood Children's Village is patterned off of some of the other promised neighborhoods including Harlem Children's Zone. And Harlem has an initiative that was focused on asthma, the Harlem Children's Zone Asthma Initiative. And as we were looking at their work and some of the efforts that they were using to combat some of the similar challenges that they're facing we began to think holistically about the children and the families that we're serving.

Shannah Tharp-Gilliam:

And anecdotally we knew that there were high asthma rates in the schools that we were serving. We had talked to some of the school nurses to try to understand the challenges that the kids were facing and they would point to the numbers of students who had inhalers. One of the football coaches, the head football coach, in fact, is one of our staff members and he would point to a bag of inhalers that he had on the sideline for students to just grab and use when they were out of breath on the field. So anecdotally we knew that there was something going on that we potentially could address if we focused on asthma. And then when we started to look more deeply into the literature and we found the high rates of asthma among African American, poor youth, it was a red light and a flag for us.

So using that information we began to, you know, partner with those who were experts around asthma because that's not our expertise. Our work is around social services and supporting kids and families and putting in academic supports. But when we called on some of our partners, particularly, this is where Michael came into the equation from the school of medicine, we came up with a strategy. But those are the primary reasons why we decided to look at asthma.

Simona Kwon:

Thank you so much. That's so interesting to hear how the whole study started. So since you were starting from, you know, a very organic place, I was really interested in understanding more about the decision to use concept mapping in the project. So what was the process for and how did HL-3 decide to use concept mapping instead of some of the other consensus building activities? And also in terms of implementing concept mapping, what types of trainings are involved?

[How] did you address in your partnership—with the individuals and folks that were helping to implement the project but also maybe with your participants? And also it would be great to learn a little bit more about whether you found this to be a flexible approach in working with both youth and adults working together in a participatory manner with both age groups?

Michael Yonas:

Yeah. Thanks. You know when we first started working and I think even working on the federal grant that was used to support some of this initiative work the team started to meet very regularly and I think organically, right, Shannah, I think it was every two weeks but then we were meeting a lot off line. But even in the design of the initiative and thinking about the proposal we really worked as an academic and community team to think what are the approaches that would be most meaningful and insightful for the approach. So we thought a lot about traditional qualitative research methods. We thought about doing survey research and, in fact, did a lot of that work as well. - Shannah, right - I think the survey developed out of some of the concept mapping findings.

Shannah Tharp-Gilliam:

Yes. Right.

Michael Yonas:

We decided as a team to use concept mapping because it was this mixed-method approach that was very participatory in nature and allowed the community and other organizational partners to help drive the research data from the start, organize and help us drive the priorities and process, but then also structured enough to help us then think about this as the first step in forming, as Shannah mentioned, other health and topic areas and intervention points moving forward.

So the concept mapping approach itself involves, I think for our team, a lot of pre-planning and I think even, you know, really careful role playing of how the concept mapping approach would work. We did an internal training of the process because we had both community and academic partners involved in each of the sessions, the brainstorming, the sorting, rating and mapping and we can maybe talk more about that if you'd like.

But even to the point that when some of the participants weren't able to attend the group sorting and rating session we had one academic project coordinator and one community project coordinator actually went to the homes of some of those individuals to do those activities as well—to try to increase, you know, the maximum participation as we could.

But concept mapping allowed for some really nice organic sort of qualitative driving of the priorities from the community—which items did people think positively or negatively impacting not just the triggering and exacerbations related to asthma, but the care of asthma as well. And then from that approach we included community partners and the participants themselves in the sorting rating again and then even the interpretation of the data.

Having young people and adults involved was something that has been done in the concept mapping literature. The concept mapping approach allows that diverse inclusion of multiple stakeholders to include them in all the phases of the process, which in our approach and Shannah, I'm just interested in your thoughts too, really helped not only just in identifying new insights and knowledge related to the impact and exposures and dynamics with asthma, but it was really an educational opportunity for all of those involved around asthma and then around the health infrastructure that exists in the community. And even interaction like Shannah mentioned within the educational system too.

But including adults and youths was ideally I think reflected the priorities of the Homewood Children's Village organizes its work, you know, much along the two gen approach which is not just addressing the needs of one individual but really the family as a whole. And it was a learning process. I think we like most qualitative approaches, you know, with the number of participants that we had it's not necessarily generalizable to the community, but we found that the findings that we had were pretty consistent with what had been learned around neighborhood exacerbations and in-home and out-of-home triggers for asthma.

But this approach allowed us to really understand some of the emotional triggers that existed in the community and the home. And particularly what young people felt and what adults felt which were sometimes consistent and sometimes not. So it was a real learning, formative phase to the work that Shannah could probably share more insight into how that's led to other work that the Village has done and HL-cubed as a group to grow from that space too. But it was also fun and, you know, a learning opportunity for everyone involved.

Shannah Tharp-Gilliam:

Yeah. Those were all really good points, Michael. I think when we first started off, you know, this was the first federally funded research study that the Homewood Children's Village had engaged in. And what I think it has done is really open up the organization to additional opportunities. How can we leverage national work to then inform the work that we do at the local level? I think we're going to talk a little bit more about that later on in the conversation, but you're right all the way around.

Shannah Tharp-Gilliam:

I mean even when we look at our strategies early on with approaches that we are really targeting youth with the in-school supports and even with the basic needs supports, the HL-cubed project really linked the second generation—the two generations—be they grandparents who were the primary caregivers of students or their parents, their mom and dad or even the aunts and uncles who sometimes fill in that role, you know, this project was really a spring board into a broader set of initiatives that we do now that we call two gen, our entire two gen aspect of our work.

Michael Yonas:

So I would just chime in. I think some other things to your question too about how the process evolved. You know we really were very conscious about how do we continue to strengthen and apply a partnership model throughout the work. So really every phase of the process, you know, involved academic and community input. We created a process for even anticipating and dealing with conflict within our team just to make sure that we were being ethical and transparent kind of throughout the process.

And that involved really our academic and well likely I think our community project coordinator reflecting back the needs and feedback from the community who were being asked to participate in this. And much like, you know, many similar neighborhoods this community has certainly been tapped to participate in research efforts and survey work from other faculty partners that weren't involved in this initiative.

And we were really particularly sensitive to that history and wanted to make sure that the people who were involved in this work, you know, we weren't using a harvesting model but really working to include them in every phase of the work as well because the Homewood Children's Village, you know, was involved in guiding this work with HL-cubed was an initiative of that effort. And so to make sure that we were transparent in all phases because the Homewood Children's Village is just doing phenomenal work in the community.

Simona Kwon:

Thank you for sharing that.

Shannah Tharp-Gilliam:

Thanks, Michael. That was very nice of you. Thank you very much.

Simona Kwon:

So I wanted to drill down a little bit more on some of the concept mapping activities and one of the things that you noted in the article was that for the session two of the concept mapping the participants were involved in sorting and rating 88 unique items and that that might have been a bit challenging for some of the participants.

But then you also report later that the process enhanced participant engagement and ownership of the data, and I really see as an example of that—I was so inspired that one of the points that was made in the lessons learned was that the participants were so engaged in the process that they started to proactively move items around from the categories and actually created a new cluster or category for the map.

And so you know, it's obviously, as you both have indicated, it was a learning process but given that finding and perhaps linking it back to the idea that the whole process actually enhanced their engagement and ownership of the data, what did you learn from the overall process and what would you have done differently or kept the same in terms of the mapping activities?

Yeah. I mean for those who, you know, I don't know how familiar the audience might be with concept mapping, but if you can imagine a stack of cards with 88 unique items on them and the participants were asked to take those cards and put them into piles that make sense to them. Right? Every individual did that and you could, you know, sort them in any way that made sense. And then people were asked to sort of put a rubber band around them and name that pile. And the way the concept mapping process works is that's done, you know, times the number of participants and then the software itself allows you to develop affinity clusters based on everyone's collective approach.

That's just time consuming and not mentally draining, but it takes a level of concentration that would stretch anyone. So we, you know, we built in some breaks. We had each of the academic and community partners were involved in kind of touching base with each person and one of my favorite visions sort of Shannah and I were talking about this in preparation for this call of her sort of sitting in this little cubby area and one young girl, she must have been eight maybe nine, ten years old I guess—

Shannah Tharp-Gilliam:

Yeah.

Michael Yonas:

—you know helping her with that process. And so it was just time consuming and you sort of just encouraged people to not look over their shoulder to say hey, how are you sorting those but to each person do it and so I think that process of investment and communication and talking and allowing everyone to realize that their unique perspective is really valued, but it just takes time. So it's really important to have really good snacks and get up, walk around and then go back to it.

But then fast forwarding to the interpretation session when we shared the clusters as they emerged from the concept mapping software itself, you know, all of this approach is designed to build on the expertise of the participants whether old and young. And we were really purposeful to ask each individual like did you agree or does that make sense to you and so when you're able to modify the map that's on the screen and to move a cluster, one of the items to a new cluster because they say oh, no as a group, your consensus that that belonged.

I think that was one of the, you know, one of the humidifier or air purifier systems belonged, you know, with appliances and not really around a trigger because somehow it had sorted there I think people realized that this is their data and their approach. And so the concept mapping process facilitated that but I think in general it reflected the priority of the group as well because we as a team I think probably could have made many decisions along the way that would have streamlined the approach and made it maybe faster and cleaner, but we wanted to really have it be as community involved in every phase as possible.

So we tried to be transparent about how that worked and just in case someone else wants to do it that, you know, you have to build in a little extra time and reach out, have a couple of sessions and things like that around the work too. But it was—I think people saw their own perspective and priority reflected in the data. And then we asked people then to help us interpret those clusters. How does this cluster relate to the care of asthma or to the triggering of asthma in the community and that's where they learned a lot from each other with adults and you know kids taking part in that process together.

Shannah Tharp-Gilliam:

Those are really good points, Michael. Just to reiterate one other facet of what you were saying, I'm a developmental psychologist by training and I've done, over the years, a lot of different data collection methods. And some of them included surveys and things that are less tangible or you're not as easily able to visualize the work that you are doing with the data collection. So one of the things I really enjoyed with the concept mapping was that it was so concrete and it was so tangible.

You know like Michael mentioned the little girl I was sitting with. She's like ten years old and she's sitting there with these cards, 88 cards spread out in front of her, and she's reading the cards. She's moving them to stacks and you could see her really processing this information, really thinking deeply about what does this mean to me. How does this reflect my experience as someone with asthma? And I could see her doing this and in even her comments and she was verbalizing and gesturing with her hands. And there was just so much involvement in the process.

And if only 90 percent of the data we collected were to generate so much enthusiasm, it would make our work a lot easier as researchers trying to collect information. Often times people feel detached from data and they don't really see it as something that is reflective of them or connected to them. So that was one of the other vivid memories that I have around collecting this information with this community. And they also responded as much as well that it really was fun doing this work.

Michael Yonas:

If I can expand on that too. It was also really interesting when they presented out as a group of how the clusters were formed and what related to what to have some of the kids themselves chime up as experts just like the adults. And I think that created a nice space where they were able to say no, this is my—as Shannah pointed out—this is my experience and my reality.

And we really put a lot of effort to make sure, you know, in the IRB discussion process and others to say that we were really there to learn from them as experts to help guide the work. Because as outsiders, even though the Village is doing so much good work in the community, this was a new space and we wanted to learn from them because it was all this work was designed and committed to be action oriented.

So this wasn't an exercise. This was really about trying to improve, you know, kids' experiences in school and in the community and to do everything we could really to help the community thrive. You know we tried to include that kind of language in I think all the work we were doing.

Simona Kwon:

Thank you for sharing that wonderful illustration of working individually with the participants as well as with the group. I think both of you also touched on this a little bit, but it would be great to hear where next steps are going, how you are applying the lessons learned to further and continue to engage with the participants and the overall partnership and to effect change around asthma in the youth community that you're serving.

Yes. This project really has had legs. After we conducted this particular aspect of the work we then further enhanced the opportunities for our youth to become researchers themselves. We had a group of teenagers—they were young men, about ten of them, who through the University of Pittsburgh, Institutional Review Board went through the process of getting certified to contribute to the project team.

And they were focused on collecting leaf samples that were then processed at a University laboratory to give us more information about the toxins and the molecules in the air that they were breathing. So those young men worked together with another researcher to put that information together into a poster and they were able to present it a couple of different times here locally and also at another conference outside of the state. So that was one way that we were able to just build on the HL-cubed work and really get the youth more involved.

We, the Homewood Children's Village, have also taken some of the results and used it as the basis for interventions. We noticed that youth who had uncontrolled asthma were more likely to have caregivers who were dealing with higher levels of stress. So we have actually partnered with some folks who provide mental health services to provide that level of support for our parents and also programs that help to provide parents with better job training and job security because financial responsibilities were also indicated to be major stressors in some of our caregivers' lives.

So that's a couple of the outgrowths from this project and we also have an aspect of our work through the Homewood Children's Village leadership institute where we are—this is another aspect of our two-generation work—where caregivers and adults in our community are being equipped with information about air quality and about other health related challenges and social determinates of health and they're getting better informed on the impact of those factors in their lives and in their community so that they can be better advocates for resources to mitigate some of those challenges that we're facing.

And actually coming up in December, Homewood Children's Village is one of the lead sponsors of the Environmental Protection Agency (the EPAs) Brownfield Conference. And we're bringing to light some of these community-based interventions and community-based participatory research initiatives and those community members are presenting out on the work that we've been doing locally in addition to bringing in regional and national experts to talk about some of these social issues that are impacting health and wellness of our communities.

Michael Yonas:

And if I could just chime in a follow-up note it's just to say that, you know, from a community-based participatory research perspective, everything that Shannah just described as the community agency partner completely owning and running and developing this entire work and research and education platform that I think, you know, this project and this paper sort of described a bit of that formative phase but it's just a really phenomenal example about capacity at the community level where they're now driving the relationship with academic partners that want to come and work with them. It's really exciting.

Shannah's leadership has been great in this space and it was really great to work with them and that team as an academic partner and you know learn to really care about the work that happens there really deeply.

Simona Kwon:

So I just want to ask if there's any last comments that you wanted to make or that—okay. Thank you so much, Dr. Shannah Tharp-Gilliam and Dr. Michael Yonas for your thoughtful comments and reflections on your work. It was so interesting to learn more about the scaffolding that supported this study and partnership and the ongoing work that is happening with your incredible partnership. So we appreciate the extra time you spent with us today and thank you again for coming on this podcast.

Michael Yonas:

Thank you so much for the opportunity.

Shannah Tharp-Gilliam:

Yes. Thanks for asking.