

## Podcast Interview Transcript

Michael Yonas, Brett Ives, Jessica Hughson-Andrade

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. The Associate Editor who handles the featured article conducts our Beyond the Manuscript interview. In this episode of Beyond the Manuscript, Associate Editor Michael Yonas interviews Brett Ives and Jessica Hughson-Andrade, authors of "Vision Voice: A Multimedia Exploration of Diabetes and Vision Loss in East Harlem."

*Michael Yonas:*

Hey, Jessica and Brett, thanks so much for the opportunity to talk and connect and learn more about your work. It's really a pleasure to talk to you more. With regard to the submission and the study that you guys presented in PCHP, I was wondering if you could just give us a little bit of background about the project and about your study and the work.

*Brett Ives:*

Great. Thanks, Michael, for speaking with us today. This work comes out of a five-year project funded by CDC as the Community Academic Coalition based at Mount Sinai in East Harlem. And it was called Communities IMPACT Diabetes Center, which sought to reduce health disparities in East Harlem.

A little bit about me—I'm a nurse practitioner and a diabetes educator. I most recently worked at Mount Sinai and became involved in this Community Academic Coalition. As a diabetes educator, I was not seeing a lot of material presented that really highlighted people's narratives—elements that would really connect and resonate with individuals and potentially mobilize communities. So that's part of the reason I became involved in the Vision Voice Project.

A little bit of background about East and Central Harlem—they're very vibrant communities culturally, and yet they shoulder a large health burden, particularly of diabetes and its complications. In East Harlem and Central Harlem, one in six adults has diabetes and one in three has high blood pressure. So, in turn, many people suffer the effects of diminished vision function and vision impairment.

In fact, in a recent survey that Communities IMPACT Diabetes Center ran along with our community partner, Lighthouse International, it was found that nearly half of people—among older adults—half of people reported difficulty recognizing the faces of family across a medium sized room and had difficulty reading regular sized print, and that includes medication labels. And this was all because of problems with vision function.

Brett Ives:

So, to address this issue, the Coalition launched multiple initiatives on vision health, and one component of this campaign was the Vision Voice Project, which is the research study that we'll be talking about today. Vision Voice served as a qualitative needs assessment. It was formative research to understand people's experiences with difficulty with vision function and how that related to managing their chronic illnesses. And this is an area that, initially, the Coalition did not know a lot about.

So, Jessica has a little bit more information on the distinction between—I keep saying low vision, problems with vision function. So what's the difference between low vision function and legal blindness or blindness?

J. Hughson-Andrade:

And I'm Jessica Hughson-Andrade. At the time of the project I worked for Lighthouse International as the outreach coordinator and was very close to the project and working with Communities IMPACT. So low vision is typically defined, or broadly defined, as a vision loss that cannot be corrected through traditional means such as eyeglasses or contact lenses.

And this vision loss will impair someone's daily function, so a little bit what Brett mentioned—unable to read medication labels, unable to basically live independently. People may have trouble recognizing faces. People may have trouble crossing the street and doing things on their own. And over time, the rates of low vision and blindness increase with age dramatically. Certainly from the ages 80 and above, we see very high rates of low vision and blindness.

And the distinction between low vision and blindness is that low vision impairs someone's daily function whereas blindness or legal blindness is typically categorized by each state. So in New York State it's defined as somebody's only able to see—their visual acuity is only of a certain degree—or their visual field (basically their peripheral vision) is only of a certain degree. And it kind of puts them in a category.

One of the challenges that we encountered at Lighthouse International is that with a lot of medical treatments coming down the pike and a lot of advances out there, people are able to retain their vision for much longer because of medical interventions, which is helping them ward off blindness. But in terms of being able to get access to rehabilitation services or assistive services or assistive devices for their vision so they can continue to stay independent with a vision loss, those services and those devices typically aren't covered until someone is considered legally blind or deemed legally blind by the state.

Brett Ives:

Just one more thing I wanted to add to your question about the background of the project—*[clears throat]* excuse me—in addition to being a form of needs assessment, we did use Photovoice in its traditional sense of being a form of participatory action research. So Photovoice, which was created by Wang and Burris in their work with women living in Chinese villages, is meant to engage people in dialog and provide a forum to reflect and express what people are seeing in their community and ideally move the group towards action.

And what is wonderful about the Photovoice approach is that it overcomes many of those barriers such as language and literacy. And I truly believe, as do others, that it has the potential for more powerful communication in the spirit of a picture speaking a thousand words. So in addition to better understanding the problem in our local community, we wanted Vision Voice

to develop strong personal narratives that could raise awareness at a community level about eye disease, diabetes, and chronic illness. And so Vision Voice is always intended to serve as an advocacy piece in that true spirit of Photovoice.

*Michael Yonas:*

Yes. I think that actually sort of leads into the next thought or question I sort of had in mind, 'cause it's really interesting, given the study population and the participants, some partners that you have in the project related to those with low and no vision. I was wondering if you could just tell us a little bit more—'cause I was particularly taken by the methods section and that sort of selection process—how media or multimedia components have evolved from this process and how the Photovoice approach, especially given the study participants, may have played out.

*Brett Ives:*

Sure. This is an important element of the project and probably the most unique aspect, is that we were using a visual medium with people who have difficulties with their vision function. To our knowledge, this is the first time Photovoice has been used with people of vision problems, as we've seen in the published literature. And so we had to be really thoughtful and creative about our recruitment and selection process and then what strategies we could use to make sure that our entire course of our research study was low vision friendly. And, obviously, this is a very important role that Lighthouse played in the project, among others.

So we recruited our participants both in the local community through our community partners, mainly Lighthouse International, through one of their projects they had running in East Harlem. And then we had our academic partners recruiting on the clinical side. And in order to select participants, the criteria included spelling out the Lighthouse International functional vision screening questionnaire to confirm that their vision function qualified—*[clears throat]* excuse me—to be in the study.

And then we—once people were enrolled in the study, we had various techniques we used so that the participants could, for example, use the cameras. Lighthouse helped us work out a couple of strategies using tactile bump dots they're called, also magnifying glasses. And they were very helpful in explaining that there needed to be good lighting, particularly in the group sessions and group presentations that we ran as part of the research study.

Regarding how the project evolved to be multimedia, we always wanted to do a true, rigorous Photovoice qualitative research study, but we also knew from the start that we would develop those narratives and turn them into a short film. And the film really brings the photographs to life. It fleshes out the women's narratives and it's obviously a wonderful medium in that it can live well beyond the timeline of the project; it can be disseminated in many different ways—particularly online and through social media. So that was always a plan, to develop the film.

What we did end up doing with the photographs and the film came out of our process with the group. The participants felt very strongly, and we went with it, to have a photography exhibit that was mobile, that moved from site to site throughout the local community. So we had the Photovoice exhibit displayed at community-based organizations. Many of our partners helped there—the university. But also on the clinical side, with the hope of raising awareness among not only the patient population, but also the health care providers. So it was displayed—the photos were displayed in waiting rooms and other clinical spaces.

*Brett Ives:*

We also tried to bring the photo exhibit to a state office building. There were just a lot of logistical and regulatory issues that got in the way of actually displaying the photos. But we did have interest from those officials. And the film also was shown in similar spaces, as I described with the photos.

And interestingly enough, just one example of how it was able to garner a much larger reach—the National Eye Health Education Program, which is part of the National Eye Institute, picked up the film and used it as a conversation piece for one of their webinars that was attended by thousands of folks—certified diabetes educators as well as people living with diabetes and vision problems. So it's very interesting to see, as we were advocating for its use, who decided to pick it up and who sought it out and used it for whatever intention they had.

And just one more plug. I wanted to say that both this film and the photographs are available on our website for dissemination, and that's at <http://www.visionvoice.cinemedical.com>.

*Michael Yonas:*

That's great. That's super helpful and actually leads into a follow-up question around it's really exciting to see how that piece was picked up and how it was used in terms of implementation or even as a tool in case study. Are there other ways in which that maybe you didn't have an opportunity, given the space within the great article, but that you see in the work that you've done really being translated into action? You know, such a core element of the CBPR process and approach in that relationship is that action component. Is there anything that has either come up since the study or things that may have been surprising to you as a team that you're maybe interested in sharing?

*J. Hughson-Andrade:*

So one of the things, one of the challenges is that we had a lot of goals for using both the toolkit and also all of the work that we had done for advocacy purposes. But we did—you know, things evolve according to abilities from each organizations' strengths, constraints, trends, and the priorities of different partnerships.

One of the great things, aside from the film and the Photovoice exhibit that came out of it, was that we created a vision health toolkit in conjunction with IMPACT Diabetes Center. We really kind of deployed a train-the-trainer model in both East Harlem and Central Harlem, empowering social service staff, senior center staff, and social workers, so that they could think about the vision health of their clients and consumers. But it was something that they had typically not addressed or even had thought of, and this really kind of brought it to the forefront.

The Vision Voice participants were also members of the vision health workgroup, so we were able to retain that community input to make sure that it was relevant, and that it was applicable, and that it was going to be picked up within the community beyond the cycle of our partnership. And they contributed quite a bit of content to the tool and the development of it and tailored it quite a bit, making sure that it was relevant. We used the data and the narratives uncovered during Vision Voice to basically inform the intervention.

As part of the toolkit, we trained social service providers to use the material, recommend regular eye exams, especially for those with diabetes. The toolkit served as an advocacy tool as well. One of the things that was really important was the promotion of regular eye care, and

one of the things that we encountered in working in East Harlem in particular is that there were very few providers of eye care. There were maybe a few optical shops, but those optical shops may not have been providing a dilated eye exam, so they really weren't detecting vision problems from the onset.

Yeah, so then another piece, as part of the advocacy, was that we hoped to drive home that for those with low vision to hopefully promote coverage by insurance so that people could obtain these aids. Particularly in areas where they're impacted by diabetes or chronic health conditions, they don't have the access nor the means to be able to purchase these types of devices and services out-of-pocket. So, throughout that project, 37 social service, faith-based, and health organizations were recruited to adopt the vision health toolkit, and what we found was quite a significant difference in receipt of comprehensive eye exams between the intervention and the control sites after six months.

*Michael Yonas:*

I mean it's just fantastic to see how that has sort of grown out. Thanks, Jessica. And I think as I've learned more in my own work and then especially from being involved and learning from you all in this process around that important distinction between low vision and no vision and the type of resources and support that are needed. I know we're getting a little short on time, but certainly as part of the—one of the elements of a participatory research process that doesn't often get talked about enough is sometimes the conflict that might occur and how to negotiate that process. And I was just wondering, with this sort of unique opportunity to share, I wonder if there were any sort of unexpected or expected lessons learned or challenges that you all experienced as a team that others might really benefit hearing about.

*J. Hughson-Andrade:*

Definitely. We certainly encountered different challenges in working together, and this is also with some input from the program manager and the Coalition lead at Mount Sinai during the time of the project—Michelle Ramos is her name just in case—because we wanted to take like a bird's eye view of what was happening across the Coalition and fold it into our work here.

So a major challenge was that the field of diabetes prevention and control was very much crowded, so a lot of groups in New York City were kind of taking on this challenge and addressing it through healthy eating mechanisms, work with children around nutrition. So there were a lot of—local communities were kind of being barraged with a lot of different efforts to address these types of issues, and they were overwhelmed as a result of it 'cause everybody was kind of doing really good work, but it wasn't happening in a concerted effort in many times.

So IMPACT—one of the things that the Coalition did was to sift through all of these issues and figure out where they could be part of this larger change and how they could figure out which areas to focus on that weren't really being served through all of these other tremendous efforts that were happening in the community. So with the help of the partners, including the Lighthouse, we identified vision health as an area within diabetes prevention and control that people weren't really talking about.

From a Lighthouse standpoint, one of the challenges that we had—kind of on an internal level—was really kind of convincing or making the case to other community partners that

this was something that was important to the work, that it was relevant to the work. I think initially it was viewed as very niche or that it wasn't something that was part of their overall goals in being involved in the Coalition. So that was kind of some of the internal push and pull that we had. And as a result of that, we kind of developed all of these different workgroups within the Coalition, so one specifically focused on vision issues, one specifically focused on healthy eating and nutrition. So that was definitely a big part of it.

*Michael Yonas:*

It's really—I mean it's—thank you, for this opportunity to learn a bit more, and I really hope that everyone has an opportunity to take a look at the manuscript. And it's great you provided the e-mail address or the website for people to kind of learn more information as well. And just in talking with you both, I know that your willingness to reach out and serve as a resource to others, you know, both in ways to maybe translate the way you operationalize the principles of CBPR so well, but then also maybe help people think through maybe ways to translate it both for your—work for your population that you've been engaged with and then other projects too. Thank you so much for sharing your time and insight with us. And I hope to connect again soon.

*Brett Ives:*

Thank you, Michael.

*J. Hughson-Andrade:*

Thank you.