

COMMENTARY: COMMUNITY PARTNER EXPERIENCES IN CPPR: WHAT PARTICIPATION IN PARTNERED RESEARCH CAN MEAN TO COMMUNITY AND PATIENT STAKEHOLDERS

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Community partners and stakeholders currently engaged in community partnered participatory research (CPPR) can provide personal and professional insight into the processes and outcomes surrounding the CPPR model. This insight may indicate alternative solutions or methods of care delivery that can improve the model and existing interventions. We conducted in-person and phone interviews with five community partners who are currently involved in CPPR. The interviews were audio- and video-recorded, transcribed, and major themes identified. Interviewees recounted their experiences with CPPR and reported various levels of personal (ie, behavioral) and professional growth as a result of their involvement. Interviewees also indicated that CPPR can highlight various aspects of existing interventions (eg, leadership structure, stakeholder representation, methods of provider-to-patient communication, and provision of resources) that may benefit from re-evaluation. Engagement in CPPR may offer various personal and professional benefits for individuals (ie, community partners) involved in stages of development, implementation, and dissemination. The benefits affect these individuals in several ways, from personal growth (eg, emotional maturity, behavioral progress, increased familial resiliency) to professional growth (eg, progression of one's career/role/responsibilities, organizational growth, learned skills). These maturation have secondary effects (eg, increased community resilience, strengthened relationships, community-based mentorships) impacting the communities in which these community partners serve. *Ethn Dis.* 2018;28(Suppl 2):311-316; doi:10.18865/ed.28.S2.311.

INTRODUCTION

The active role of community stakeholders in community partnered participatory research (CPPR) is necessary to ensure fair, equal, and equitable representation of the communities they serve. In CPPR, community partners are viewed equally in research development, implementation, and dissemination.¹ In this commentary, we highlight information from interviews we conducted with five community partners, three from Los Angeles and two from New Orleans, who share the stories of their involvement in CPPR. Together,

their voices offer insight into the impact this model has made on both their communities and their personal and professional lives.

COMMUNITY PARTNERS SPEAK OUT

Adding Community Voice to Research

It all began with a missing voice. Pluscedia Williams, or Ms. Plus, as she is known in her community, was invited to attend a meeting for the Los Angeles-based project Witness4Wellness, a collaborative academic-community participa-

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tory partnership designed to better understand depression in under-resourced communities. From our personal interview² with Ms. Plus, we learned that, as she listened to health providers and researchers discuss depression from a clinical point of view, she grew frustrated and responded with a simple yet poignant question, “How many of

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you deal with depression personally?” Ms. Plus, who has lived with major depression, looked around the room and noticed only one hand was raised, her own. She continued, “You only know what you read in books. I deal with depression. I’ve tried to commit suicide three times. It hasn’t worked because I’m here

talking to you.” It was this voice that had been absent at the table from previous meetings: a voice of a person living with a mental illness, a voice that represented the many people who struggle with depression but do not have the opportunity to attend community meetings—a voice to share the other side.

As a decades-long, active member of her Los Angeles community, and as an individual who has lived with depression since childhood, Ms. Plus exemplifies many of the traits that make an ideal community partner. From her experience working with the Lynwood Unified School District to the work she has supported at Charles R. Drew University and UCLA, her professional experience demonstrates a wide-ranging knowledge of the tools and services used to engage the community—particularly those involved in the field of mental health.

Ms. Plus’ personal experience with depression has allowed for deeply intimate connections to those with whom she works closely, cultivating the astute investigative spirit she is known for across the country. It was not until her early twenties, however, while acting as Union President for Lynwood Unified School District, that she would gain insight into her own mental health, encouraging an introspection that would later fuel and provide strength to her role as a community leader and advocate for the under-resourced in mental health.

“I think that it’s just important that we be open and honest with one another. I know there are some things you can’t say or tell,

but I think that you need to learn how to trust us, because we’re trying to learn how to trust you.”

Throughout the years, Ms. Plus has had the opportunity to work on several projects, such as Witness 4 Wellness, each a progression on the CPPR model. In this respect, along with her natural capacity to pose the right questions and challenge those who may not be aware of alternate solutions—she can provide the insight necessary to further advance the CPPR model. “It doesn’t matter if you’re Black, White, Mexican, Asian, or whatever—the same things happen because researchers don’t want to listen to you, because they have all the answers. I’m trying to get them to understand that they need to appreciate who they’re researching. They need to educate us. Then, I try to tell the community, ‘You need to ask questions, because there’s something they haven’t thought of yet.’ They might be looking at something else, but they should be looking at this instead of that.”

On the topic of interaction between patients and their providers, Ms. Plus proclaims a necessity for clear and direct communication, indicating a certain disconnect that may be present in current studies that employ the CPPR model, and in others that are desperately in need of it. She insists that in order to communicate effectively with patients, you must communicate at the patient’s level and tell the truth.

Today, working as a consultant with UCLA—in addition to being on the scientific advisory council at LA Biomed—Ms. Plus is a liv-

ing testament to the various personal and professional benefits that may arise from one's involvement in CPPR, and the strong impact a community partner can have on researchers. Her professional experience working in the field of mental health research, along with her history of depression, has undoubtedly nurtured a remarkable ability to act as a liaison between academia and the community.

"In the future, I see academia and community working together more. I want to deal with people. A lot of researchers deal with animals, or they deal with sales, but they don't deal with the person. I want to deal with the person... I really hope that academia will get to the point that they won't do anything without community."

Using Life Experiences to Shape Programming

Diagnosed with schizophrenia as a young adult, Jose Flores is another example of someone whose personal experience with mental illness has equipped him with the skills to thrive as a mental health community-based partner. Through our personal interview with Mr. Flores,³ we learned that he was born and raised in San Benito, Texas, relocated to Delano, California and has dedicated his life to helping others with mental illnesses, especially after an incident of bullying led him to take a stand and promote resiliency.

In high school, farm labor became his source of income. The United Farm Workers Union, which was in its developmental stages during this time, encouraged Mr. Flores

to become more involved with the community. He began working with students from California State, Long Beach to develop a school for Head Start, an organization that provides comprehensive education and health services to low-income children and their families.

Currently, Mr. Flores works as a housing specialist for the Project Return Peer Support Network in Commerce, California. This county-contracted, non-profit agency provides resources and opportunities for people with a mental illness. For Mr. Flores, he has made it his mission to utilize community partnered research to discover more solutions for those living with a mental illness: "There's a lot that can be done during the time you get up and go to bed and it doesn't always involve medication and that's my continued effort to find more about what to do for people in the community."

With his work on two community partnered projects, Recovery International and Procovery, Mr. Flores helps individuals to better understand their mental illness and potential aids to recovery. He explains:

"Community partnered research means the need for agencies and researchers to not be ambivalent in allowing people to continue to suffer in the community with their lived experience, and to identify possible alternatives to what they're doing now."

Mr. Flores notes that there may be challenges for community partnered research, especially when it comes to locating funding sources and outlining acceptable outcomes for funders. He emphasizes the im-

portance of sharing stories within communities, and, to this day, looks for common spaces in which others can meet and share their stories.

"By allowing individuals to understand my story, be part of my life, and acknowledge that they, too, can reach out and allow people to learn and be educated

"Community partnered research means the need for agencies and researchers to not be ambivalent in allowing people to continue to suffer in the community with their lived experience, and to identify possible alternatives to what they're doing now." as stated by Jose Flores, mental health community-based partner

about what they're experiencing and how they can become involved are now part of a solution."

From his early involvement with community at a young age to holding a seat on the board for Disability Rights California, while working at the non-profit Project Return for the last 17 years, Mr. Flores views community partnered research as a

national movement and one with which he will persistently engage.

Participant and Provider

While Ms. Plus and Mr. Flores brought insight to the community as patient stakeholders, Ms. Andrea Jones has a compelling story with CPPR identifying as both a participant and provider, as told to us during our personal interview.⁴ In 2004, she worked with the Los Angeles non-profit, Healthy African American Families (HAAF) as a volunteer and within three months, became their receptionist and was asked to sit in on meetings and take minutes. Her role then expanded to becoming a project coordinator where she now creates surveys, analyzes data, and writes grants.

Being a “change agent,” “bridge-builder,” and “gatekeeper” are some of the words she uses to describe herself and other community health workers (CHW). She explains that CPPR is truly about bringing communities and health agencies (in this case, universities) together in a space where everyone is equal and all voices are heard and acknowledged. Remembering a specific case where she was working on a wellness project with both academic health researchers and community members Ms. Jones explains: “All the community members were on the same page. We all had the same note that it [a survey answer] means this, and the researchers looked, and they were like, “We would have never thought of that.” Because you don’t live in the community we live in. We have a different perspective.”

Ms. Jones shared that CPPR is

not without its challenges, particularly when moving a project from paper into practice. Recruitment can be a challenge, as well, as participants will unexpectedly drop out of projects. However, the largest challenge that she faces is relationship building. Ms. Jones explains that people are not always on the same page in regard to how something should be implemented or analyzed. She notes that relationship building is about pushing through the small everyday challenges and not walking away - that is how one becomes successful in the long run. Her greatest take-away is that CPPR can ensure the progress and success of mental health services by “making sure community is at the table - by keeping us at the table - to allow us to have an input into the process.”

Love for City and Its People Inspire Community Partnered Work in New Orleans

About 1800 miles from Los Angeles in New Orleans, Louisiana, Angela “Angie” Kirkland and Catherine Haywood extend their love for their city and its people with their community partnered work. Ms. Kirkland is currently a community health worker (CHW) at Tulane University. Highlights from her personal interview⁵ indicate that, as her work shifted from the clinic to community health work in neighborhoods, she often meets clients at their homes, grocery/corner stores, and even bus stops to ask about their health needs and how she could connect them to resources.

Ms. Kirkland’s involvement in community-academic partnership

began 12 years ago in 2005 when Hurricane Katrina devastated New Orleans. Her extensive experience in community health work and mental health were instrumental in the Reach NOLA project, a mental health resiliency project in which staff at community agencies and health care providers are trained together to collaborate and provide effective mental health care for persons affected by natural disasters. As a CHW, she went door-to-door to provide support and resources for community members who were struggling with post-traumatic stress disorder and severe depression.

With her profound involvement in the community, Ms. Kirkland sees the benefits of CPPR as a mutual “sounding board” for both academic and community partners. CHWs and community partners inform academics of cultural norms and community perspectives of a health topic to more accurately form hypotheses and conduct research.

She envisions the future of CPPR projects as a team that needs more players from every level, from families and caretakers to physicians and academics. “Families need to be involved, the psychiatrists, the social workers...when everyone is involved the whole community is healthy.”

With more community participants, either as members or health workers, Ms. Kirkland strongly feels that the community as a whole is healthier and happier; and academic research is more accurate, has a wider scope, and provides more information to community-based health workers. As is evident in her past and current work, she believes

that passion, commitment, and love for people from both academic and community partners creates healthier communities and better research.

According to our personal interview with Ms. Catherine Haywood,⁶ she has dedicated the last 27 years of her life to New Orleans by being a spokesperson for those who are often “voiceless” and “unseen.” In 1989, Ms. Haywood along with a few other community advocates founded the nonprofit, Women with

It is their resounding voices that inspire others to raise theirs, educating the community and researchers, and building on their own resiliency to make an impact on their community.

A Vision (WWAV), in response to the HIV/AIDS epidemic occurring in communities of color. In almost two decades, WWAV has become a force in the community to improve the lives of marginalized women and families by addressing health and social service disparities within communities of color by partnering with other community stakeholders and participating in CPPR.

For Ms. Haywood, addressing these disparities is imperative to

making sure that community voices are heard by academic researchers in order to work together in fixing these issues. One of the underlying challenges she has noticed is that many times researchers go to the community with scientific questions already formulated without allowing community members to provide feedback and express questions they want answered. Ms. Haywood expressed that work needs to be done to educate the community about how research works so they “. . . trust in what’s being done in the research field because a lot of times they just don’t trust universities and they don’t want to do anything in research because they feel they’ve been used.”

Ms. Haywood believes that there is still much more work to be done to secure the success and progress of community partnered research in communities of color. However, she believes that by properly educating the community about the purpose and importance of research and concurrently educating researchers about the importance of treating the communities they work with as equal partners, we will come one step closer to bridging the gap between academics and community in finding solutions to the health and social service disparities.

CONCLUSION

These five voices have distinctive messages that have a powerful connection that clearly unites them. It is their resounding voices that inspire others to raise theirs,

educating the community and researchers, and building on their own resiliency to make an impact on their community. Thus, a spirited ripple effect is created among community partners across the nation. Ms. Plus concludes:

“People need to know that there are really people who are like them. If they always see doctors, social workers, nurses, they can’t identify with them because some of them haven’t even gone to high school; some of them haven’t graduated high school; some of them have dropped out; they have babies; they have this; they can’t take care of themselves. I didn’t think I was valuable...and now I talk about it. I found out that I am valuable, but I had to come to the understanding that I am somebody, and I’m just like you. I might be a different color, might be a different age, but I can learn from you, and I learn from everybody—children, adults, whatever. My daughter says, ‘Mama, you’re not lost. You’re discovering new territory.’”

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CONFLICT OF INTEREST

No conflicts of interest to report.

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