Applying Community-Partnered Participatory Research Approaches to Develop COVID-19 Solutions

Kenneth Brooks Wells MD MPH;[1,2]
Felica Jones,[3] Keith C. Norris MD, PhD[4]

Ethn Dis. 2020;30(3):433-436;
doi:10.18865/ed.30.3.433

Keywords: Community-Partnered Participatory Research; COVID-19; Team Science

[1] Center for Health Services and Society, Jane and Terry Semel Institute, Department of Psychiatry and Biobehavioral Sciences, David Geffen School of Medicine, Department of Health Policy and Management, Fielding School of Public Health at UCLA, Los Angeles, CA
[2] RAND Corporation Health Program, Los Angeles, CA
[3] Healthy African American Families II, Los Angeles, CA
[4] Division of General Internal Medicine and Health Services Research, David Geffen School of Medicine at UCLA, Los Angeles, CA

Address correspondence to Kenneth Brooks Wells MD MPH; Center for Health Services and Society, Jane and Terry Semel Institute at UCLA, 10920 Wilshire Blvd., Suite 300 Los Angeles CA 90024; kwells@mednet.ucla.edu

Introduction

Community engagement is critical in working with under-resourced communities in program development, evaluation and research,[1] and becomes even more essential in times of crisis, such as COVID-19. The authors of this perspective have collaborated for more than 15 years in community-partnered participatory research (CPPR)[2-5] focusing on health equity, even in times of disasters.[6,7] Recent inquiries from our community partners about how CPPR may be applied in partnered program evaluation of COVID-19 actions led to a review of lessons learned in applying CPPR to Community Partners in Care (CPIC).[8] This perspective offers thoughts from a lead community partner as well as academic and community partner reflections.

Community Partners in Care (CPIC) was a group-level randomized trial of two interventions using CPPR to implement community-wide collaborative care for depression.[7] Two intervention models were assessed: a) multi-sector coalitions and b) technical assistance for individual programs. The study included 95 agencies in Los Angeles; findings reported improved outcomes for depressed clients when the multi-sector coalition was used compared with the technical assistance model, at 6-12 months and 3- and 4-year follow-up.[8-11] These findings were cited in a Cochrane Collaborative Review as a rigorous study of the added value of coalitions in addressing health disparities.[12] Because of their work in CPIC, more than 100 Los Angeles-area community and academic partners won the 2014 Team Science Award from the Association of Clinical and Translational Science.

Recent inquiries from our community partners about how CPPR may be applied in partnered program evaluation of COVID-19 actions led to a review of lessons learned in applying CPPR to Community Partners in Care (CPIC).[8]

Lessons to Apply to COVID-19 Solutions

In March 2015, after receiving the Team Science Award, the academic lead (Wells) and Loretta Jones, the community lead, discussed lessons learned for the future of team science under CPPR. Dr. Jones passed away in November 2018 but her comments from this discussion remain important to today's work in CPPR as it can be applied COVID-19 solutions. Here, we share her remarks with interpretation from community and academic partners in CPPR and CPIC and illustrate how lessons of CPPR can be applied to partnered team science research today. In her reflections during the March 2015 discussion, Dr. Jones answered two questions: What have we learned from CPIC and what are lessons for Team Science? Her responses are summarized below.

Trust

Dr. Jones emphasized developing trust through "authentic partnership," which may differ from usual partnerships. Co-equal leadership respects expertise of community and academic partners and considers different perspectives and implications for projects and outcomes. She emphasized how working through disagreements respectfully is a cornerstone of trust.

Culture

Dr. Jones noted the importance of attending to current a) community issues, such as discrimination or gentrification; and b) cultural history, such as racism in research. She emphasized talking through issues even if uncomfortable, including when academic members seem insensitive to community perspectives. She commented that this requires open discussion: "Stop what you are doing and listen or people may walk away." It is important to know that people want and deserve their issues to be acknowledged, for "trust to be at the top of the table." It is important to respect differences and "agree to disagree."

Defining Partnerships

Dr. Jones highlighted, "knowing that all voices matter." This means "learning how to meet people, make introductions – understand expectations, what you can do to meet them, and following through." It means knowing "who the community is as defined by the community," and asking "who is not at the table?" This is followed by engaging members to keep partners informed and present. In addition, an authentic partnership means maintaining a "resilient environment" and understanding that "people may have struggled to maintain ownership and dignity," which the partnership should honor and promote.

Words

Dr. Jones emphasized the importance of how words are used, including "disadvantaged, underserved, and empowerment," that may "label" communities negatively. It is important to understand that "people have power when they wake up in the morning," or inherent power which can be redirected. Dr. Jones noted: "See the words missing in your dialogue" such as resiliency and respect; and "remember the R's (respect, resiliency) as well as E's (engagement, empowerment)."

Analysis

Dr. Jones underscored the importance of communities partnering with methodologists, to "define questions" and ensure that all team members "understand analysis structure and approaches." Such two-way interactions can result in obtaining, analyzing and interpreting data that reflect community perspectives, enhancing use of data to inform policies that align with community priorities.

Results

"What's happened to people?" Dr. Jones emphasized, "What are the 'victory stories' or impacts at all levels? What were the challenges faced, and how were they overcome?" It is important to determine who was instrumental to victory, and to whom attribution should be given. Answering such questions helps explain impacts, gives examples to encourage others, and ensures partner recognition.

Challenges

Dr. Jones noted challenges, including members' comfort with issues, institutions, or approaches, and the need to ensure meaningful sharing of opportunities. Within and across partners, there may be different "agendas." Funding is a major issue to support community participation; community should participate in fund-seeking/financial planning and allocation. All financial steps should be transparent. Challenges in outreach to communities, including ethics and histories of interactions, require trust-building through ongoing engagement, such as the engagement of African American churches to advance

health promotion interventions for mental health issues and more.[13,14]

Equality and Equity

Dr. Jones emphasized equality and equity (ensuring that resources are distributed equally and appropriately for level of need). It is important to ask, "Who is it for?" keeping community and academic benefit in mind, requiring training and commitment to two-way knowledge exchange, to achieve a "win-win" for all participants.

Difficulties

Dr. Jones noted a primary "difficulty" is developing and maintaining trust, given histories of mistrust. She noted the importance of asking, "Who is with us? Are we together?" To prompt redirection, leaders should ask themselves, "Are we talking smack?" or "Are we not listening to the community?"

Infrastructure

Dr. Jones highlighted the importance of "transforming environments" to facilitate interaction and engagement that enhances community capacity and improvements, by asking "What does it lead to?" This involves monitoring impact for equity and equality in priorities, approach, and resources, to develop community capacity.

Education

Dr. Jones emphasized education, including workbooks for consistency in approach, exercises that make engagement a "living trust" and having partnered teaching for community and academic leaders. She emphasized "readiness," or ongoing partnerships in place so that communities can respond to emerging needs or crises, in trusted partnership. Dr. Jones re-iterated the "importance to community of science, and breadth of science" to benefit communities and science. "That," she noted, "is partnered team science."

Implications

In considering Dr. Jones' lessons learned from CPIC in context of COVID-19, we note several recommendations and limitations. First, many communities may not have a history of partnership with academics under a two-way knowledge exchange to facilitate immediate, authentic partnerships. Others may have this in place but must attend to current context (remote interaction, system and community needs and capacities). It may be helpful to acknowledge histories and common goals, even by remote communication, to share priorities and models, expecting further input and modification in follow-up.

Across communities, issues, such as social isolation/distancing, economic challenges, and health care strains may offer opportunities for shared learning (eg, mental and emotional health check-ins, protected Internet time for partners in digital deserts, coordinated shopping activities and more). The academic partner needs to recognize that the privilege of social distancing often does not extend to community partners who live in under-resourced communities as well as the potential mental health impact of social isolation,[15] especially for those without cars and with limited social networks. This may be exemplified by the need to approach communication carefully and respectfully, using some of the approaches needed when multiple generations live in one home where consistent private conversations with full attention are affected.

In times of crisis, it is critical to first establish potential shared goals, discuss modifications to research protocols and attention to community priorities in content, communication and design. In some respects, this was the context for CPPR application to prior disaster preparedness and recovery efforts.[5,6] Yet, it may be important to attend to CPPR lessons learned as summarized above. While this may not assure success, it builds on an evidence-based team science model that can inform building authentic partnership for health concerns, including in times of stress. In

In such times of crisis, it is critical to first establish potential shared goals, discuss modifications to research protocols and attention to community priorities in content, communication and design.

fact, Dr. Jones, the lead community partner providing these comments, was particularly concerned about the impact of public health disaster events on under-resourced communities, in prioritizing and designing partnered research. Her prescient vision provides important lessons that may be even more relevant in the time of COVID-19 where there may be the sense of pressure to act unilaterally. If we are to advance science from effective mental health strategies during isolation to vaccine development, antibody testing and more, the use of CPPR principles is critical to ensure the advances from science accrue equally to all communities.

Acknowledgments

The authors acknowledge funding support from NIH/NIA Grant P30-AG021684, NIH/NCATS UCLA UL1TR001881, and RWJF Community Leadership Conference grant.

References

1. Smedley BD, Syme SL; Committee on Capitalizing on Social Science and Behavioral Research to Improve the Public's Health. Promoting health: intervention strategies from social and behavioral research. *Am J Health Promot*. 2001;15(3):149-166. https://doi.org/10.4278/0890-1171-15.3.149 PMID:11265579
2. Jones L, Wells K, Norris K, Meade B, Koegel P. The vision, valley, and victory of community engagement. *Ethn Dis. 2009;*19(4 Suppl 6):S6-3-7. PMID: 20088076
3. Jones L, Wells K. Strategies for academic and clinician engagement in community-participatory partnered research. *JAMA*. 2007;297(4):407-410. https://doi.org/10.1001/jama.297.4.407 PMID:17244838
4. Wells K, Jones L. "Research" in community-partnered, participatory research. *JAMA*. 2009;302(3):320-321. https://doi.org/10.1001/jama.2009.1033 PMID:19602693
5. Del Pino HE, Jones L, Forge N, et al. Integrating community expertise into the academy: South Los Angeles' Community-Academic Model for Partnered Research. *Prog Community Health Partnersh*. 2016;10(2):329-338. https://doi.org/10.1353/cpr.2016.0028 PMID:27346780
6. Springgate BF, Allen C, Jones C, et al. Rapid community participatory assessment of health care in post-storm New Orleans. *Am J Prev Med*. 2009;37(6)(suppl 1):S237-S243. https://doi.org/10.1016/j.amepre.2009.08.007 PMID:19896025
7. Wells KB, Tang J, Lizaola E, et al. Applying community engagement to disaster planning: developing the vision and design for the Los Angeles County Community Disaster Resilience initiative. *Am J Public Health*. 2013;103(7):1172-1180. https://doi.org/10.2105/AJPH.2013.301407 PMID:23678916
8. Wells KB, Jones L, Chung B, et al. Community-partnered cluster-randomized comparative effectiveness trial of community engagement and planning or resources for services to address depression disparities. *J Gen Intern Med*. 2013;28(10):1268-1278. https://doi.org/10.1007/s11606-013-2484-3 PMID:23649787
9. Chung B, Ong M, Ettner SL, et al. 12-month outcomes of community engagement versus technical assistance to implement depression collaborative care: a partnered, cluster, randomized, comparative-effectiveness trial. *Ann Intern Med.* 2014;161(10_Suppl) S23-S34. https://doi.org/10.7328/M13-3011 PMID: 25402400
10. Ong MK, Jones L, Aoki W, et al. A community-partnered, participatory cluster-randomized study of depression care quality improvement: Three-year outcomes. *Psychiatr Serv.* 2017;68(12):1262-1270. https://doi.org/10.1176/ appi.ps.201600488
11. Arevian A, Jones F, Tang L, et al. Depression remission under community coalition versus individual program support for services: Findings from community partners in care, 2010-2016. *Am J Public Health*. 2019;109:S205-S213. https://doi.org/10.2105/AJPH.2019.305082 PMID:31242001
12. Anderson LM, Adeney KL, Shinn C, Safranek S, Buckner-Brown J, Krause LK. Community coalition-driven interventions to reduce health disparities among racial and ethnic minority populations. *Cochrane Database Syst Rev*. 2015;6(6):CD009905. https://doi.org/10.1002/14651858.CD009905.pub2 PMID:26075988
13. Hankerson SH, Wells K, Sullivan MA, et al. Partnering with African American churches to create a community coalition for mental health. *Ethn Dis*. 2018;28(suppl 2):467-474. https://doi.org/10.18865/ed.28.S2.467 PMID:30202200
14. Campbell MK, Hudson MA, Resnicow K, Blakeney N, Paxton A, Baskin M. Church-based health promotion interventions: evidence and lessons learned. *Annu Rev Public Health*. 2007;28(1):213-234. https://doi.org/10.1146/annurev.publhealth.28.021406.144016 PMID:17155879
15. Galea S, Merchant RM, Lurie N. the mental health consequences of COVID-19 and physical distancing: the need for prevention and early intervention. *JAMA Int Med.* April 10, 2020 [Epub ahead of print]. https://doi.org/10.1001/jamainternmed.2020.1562