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Using Stakeholder Input to Inform an Innovative Research and Policy Initiative to Improve Depression in Safety Net Communities

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Abstract

The Problem: Depression quality improvement (QI) programs based on chronic disease management models have been shown to improve depression outcomes. Nonetheless, access to and the use of such programs is limited in minority, under-resourced communities.

Purpose: We report on the outcomes of a Delphi-based consensus exercise conducted by our partnership at a community-wide conference in Los Angeles. Participants identified and prioritized the needs of depressed individuals that should be addressed in a county-wide Health Neighborhood Initiative (HNI) designed to increase existing mental health, substance use, health care, and social services for individuals with low socioeconomic position (SEP).

Lessons Learned: Participants agreed that housing is the number one priority. Delphi results also illustrate the importance of addressing social, spiritual, and health care access needs of depressed individuals.

Conclusions: Our study shows how to systematically engage community-based organizations, patients, families, and community members in the process of improving the design of community-wide health policy initiatives.

Keywords

Community engagement, Delphi, depression, Los Angeles, mental health policy

Depressive disorders are the leading cause of adult disability in the United States,[1,2] are associated with reduced quality of life, and are risk factors for physical health problems.[3] Although depression is prevalent in all ethnic groups, compared with Whites, racial/ethnic minorities have less access to evidence-based depression care and worse treatment outcomes.[4] Similarly, individuals with lower SEP (i.e., low educational attainment, low income) tend to have higher rates of depression than more affluent individuals.[5]

Depression QI programs based on chronic disease management models have been shown to improve depression outcomes,[6,7] particularly for minority and low SEP populations. Nonetheless, access to such programs is limited in minority, under-resourced communities.[8] Furthermore, improvements in mental health outcomes may be complicated by comorbid medical conditions and increased exposure to social determi-

nants of health, or conditions in the environment in which people live and work, including poverty, unemployment, and lack of health insurance.[9–13]

Results of the Community Partners in Care (CPIC) study (http://www.communitypartnersincare.org), a cluster-randomized controlled trial, show the benefits of a partnered approach to designing a community-wide depression QI program. CPIC findings suggest that, compared with providing technical assistance to agencies, engaging diverse health care and community-based agencies in planning and implementing a depression QI program in their community[14,15] improved mental health-related quality of life, increased physical activity, reduced homelessness risks factors and behavioral health hospitalizations among depressed individuals, and shifted delivery of mental health services toward community-based agencies.[16,17]

Based on CPIC findings, the Los Angeles County (LAC)

Board of Supervisors added the Department of Mental Health's (DMH) HNI[18] to the LAC's strategic plan. HNI was designed to increase existing mental health, substance use, health care, and social services for low SEP minorities. DMH leadership invited CPIC partners to support HNI's development to ensure its relevance and cultural appropriateness for communities distrustful of research and publicly funded services.[19,20] In preparation, academic and community members of the CPIC study steering council conducted a community-wide conference[21,22] to share CPIC findings and engage patients, providers, and representatives of community organizations in identifying HNI's main focus. The main conference activity was a Delphi-based consensus-building exercise[23,24] to assess community needs and prioritize social determinants of mental health to be addressed within the HNI. The Delphi method is based on the idea of iterative data collection, which allows participants to learn about and discuss the responses provided by others and then revise their answers in light of the discussion. This method has been used successfully in other studies to assess community needs and priorities.[23,24]

The goal of this manuscript, which was written by CPIC academic and community partners who have been working together for more than 7 years on a wide range of community-academic partnered mental health research projects, is to describe and summarize the Delphi process and its results to 1) illustrate how community-based organizations, patients, families, and community members could be systematically engaged in the process of designing community-wide health policy initiatives, 2) show how community engagement has already affected HNI design and implementation, and 3) explain how community engagement could be used for collaborative policy planning in other communities. Our manuscript illustrates how participatory research partnerships can support policy development and implementation at the local level by informing policymakers about community preferences and needs and working with them on designing large-scale interventions that are likely to be accepted within community.[25]

METHODS

The community conference co-organized by academic and community members of the CPIC steering council took place on September 12, 2014 in South Los Angeles, a predominantly minority, low SEP community. Eighty-six stakeholders from South Los Angeles and Hollywood, including people with depression, mental health professionals, DMH employees, social workers, researchers, case managers, and clergy, all of whom had a significant experience and expertise in either dealing with, or helping those suffering from, depression attended this conference. Most attendees had also participated in previous local, community-based, long-term, community–academic partnered research initiatives and were knowledgeable about research process and the needs of depressed individuals living in Los Angeles. Conference attendees were not compensated for their time, but were served breakfast and lunch and were eligible to receive CME/CEU credits.

Conference attendees participated in a two-round Delphi-based exercise,[24] which was co-conducted by an academic (D.K.) and a community (P.W.) partner, who worked together to develop a Delphi protocol, design data collection sheets, and determine the best analytic approach. All data collection activities were reviewed and approved by the RAND's Human Subjects Protection Committee.

We chose a Delphi approach, instead of a survey, to allow participants to respond based on their own professional and personal experience first, and then to revise their initial responses based on the new information they received during the conference.[23] In round 1, participants rank-ordered eight needs of depressed individuals with the goal of prioritizing the needs to be addressed first so the HNI could have the greatest likelihood of improving depressed individual's overall well-being. Participants were instructed to consider how much the overall wellness could be improved if not only low mood, but also each of these needs, or social determinants of mental health, could be addressed. The needs, which participants rank-ordered from 1 (highest impact) to 8 (lowest impact), included finding housing, accessing quality health care, improving relationships with others, improving spiritual well-being,* finding work, getting benefits (i.e., unemployment, food stamps), improving mental wellness, and combatting racism and racial violence.

The first six needs were identified as part of an ongoing qualitative study of people living with depression (see below);

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* Spiritual well-being is defined as covering individuals' inner life and its relationship with the wider world. Spiritual well-being is about a sense of wholeness, which encompasses the religious, physical, emotional, and mental dimensions

the last two needs were suggested, discussed, and agreed upon by conference attendees immediately before the first round of ranking. During the study design stage, P.W. suggested that conference attendees should be allowed to propose additional needs, whereas D.K. stressed the importance of limiting the number of additional needs proposed and ensuring that all participants rank order the same set of needs. Therefore, by working together, academic and community partners developed a mutually agreed upon research design.

After round 1, participants heard a brief presentation about the ongoing community–academic partnered qualitative study on social determinants of mental health. Based on in-depth telephone interviews with 104 depressed Angelenos,[†] improving mental wellness, accessing quality health care, and finding housing were identified as the top needs. After lunch, conference attendees were divided into 11 discussion groups to share their round 1 rankings and explain why they felt that addressing a certain need would have the greatest impact. Trained community or academic partners facilitated discussion groups using a semistructured protocol and encouraged participants to explain how collaboration among community agencies could help to address these needs. Notes were taken during the discussion by the facilitators to capture participants' reasons for ranking a given need as their top priority. After discussion, participants who did not leave the conference after lunch provided their round 2 rankings of needs.

We used two analytic approaches to rank order the needs to ensure robustness of our findings. We first rank-ordered the needs based on the mean ranks and then based on the percentage of participants selecting a particular need as their top priority. We qualitatively summarized participants' discussion comments related to each need to contextualize ranking results. In particular, we were interested in understanding why some participants ranked a given need highly, whereas others did not do so.

RESULTS

Seventy-five percent of participants were female and 43% were African American. Twenty-nine percent represented mental health agencies, 19% were community members (including depressed individuals), 16% represented social services agencies, and the remaining 36% represented religious, primary care, substance abuse, homeless, public health, and academic agencies/institutions.

Results are based on the input from 68 participants answering all ranking questions in both rounds (79% of conference attendees). Seventy-four percent of participants changed at least one of their answers between rounds. When ranks were changed, the typical change was plus/minus one ranking place, and it did not affect the top priority.

Table 1 displays means and standard deviations of each need's rank. It shows that the top need in both rounds was finding housing. Roughly one-half of all participants rated housing as their number 1 or 2 choice in both rounds (data not shown). Group discussions revealed that housing is essential for providing a sense of security and stability and is crucial for

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[†] As part of the CPIC study, individuals were screened for depressive symptoms using the eight-item Patient Health Questionnaire.[16]

Table 1. Ranking of Needs Based on the Mean Values (*n* = 68)				
	Round 1		Round 2	
Rank	Need	Mean (*SD*)	Need	Mean (*SD*)
1	Finding housing	3.15 (2.046)	Finding housing	3.19 (2.068)
2	Accessing quality health care	4.13 (1.836)	Finding work	4.22 (2.258)
3	Finding work	4.18 (2.239)	Improving spiritual well-being	4.31 (2.111)
4	Getting benefits	4.41 (2.111)	Accessing quality health care	4.34 (1.728)
5	Improving relationships with others	4.68 (2.126)	Getting benefits	4.59 (2.180)
6	Improving spiritual well-being	4.76 (2.253)	Improving relationships with others	4.81 (1.926)
7	Mental wellness	4.91 (2.708)	Mental wellness	5.07 (2.830)
8	Combatting racism	5.49 (2.269)	Combatting racism	5.34 (2.459)

Note: The table shows the mean ranks and standard deviations of each need in Rounds 1 and 2. The lower the mean, the higher impact participants assigned to a need.

mental health recovery. Housing was followed by the needs to access quality health care and to find work in round 1, and the needs to find work and to improve spiritual well-being in round 2. Participants often discussed finding work and finding housing together, referring to them as "basic" needs that should be addressed first. Finally, although addressing mental wellness and combatting racism were at the bottom of the list in both rounds, getting benefits and improving relationships with others were consistently in the middle. In discussing racism and associated violence, for example, participants often felt that this was a long-term goal and that violence in communities is not only related to racism. Although some ranked it highly, considering racism to be a fundamental problem, others felt this need was a broader societal issue that cannot be addressed at the level of just one neighborhood.

Table 2 presents Delphi results based on the top need chosen by each participant. Although finding housing remained the top priority in both rounds, mental wellness and spiritual well-being moved up to the top of the list, and access to health care moved to the bottom. Participants varied in their perspectives on addressing mental wellness: whereas more than one-fifth of participants considered this need to be their top priority in both rounds, one-quarter of round 1 participants and roughly one-third of round 2 participants put it at the bottom of their list. To describe mental wellness, participants used a variety of terms, including joy, mindfulness, and self-esteem. Those who prioritized mental wellness often argued that mental wellness encompasses other needs and is the basis for taking care of all other needs. They stated that being mentally well helps people to make good deci-

sions about themselves and people around them, which is a prerequisite for helping others. Those participants, especially clinicians, who put this need at the bottom of their lists often felt that mental wellness was already included as a component of other needs and therefore should not be prioritized on its own. Finally, in ranking access to health care, the majority of participants placed this need consistently in the middle of their lists, with only 6% making it their top priority. Although some participants felt that access to quality health care was very important for addressing mental health needs, others argued that addressing health care needs was not as important as addressing some other needs on the list.

DISCUSSION

Our results illustrate a wide range of opinions about how best to help depressed Angelenos, which may be partially explained by the diversity of conference attendees' backgrounds and complexity of the issue. Conference attendees, however, agreed that community-wide collaborative efforts to address depression among ethnic minority and low SEP populations in LAC may have the highest impact on the overall well-being of depressed individuals if community agencies can help them to find stable and affordable housing. Indeed, housing was ranked number 1 in both rounds and using both analytic approaches.

Addressing unemployment, emphasizing mental and spiritual well-being, and facilitating access to quality health care were also deemed important. These findings suggest a strong community preference for a multiprong HNI that addresses not only social (housing and employment), but also

Table 2. Ranking of Needs Based on Participants' Top Priority (*n* = 68)					
Round 1			**Round 2**		
Rank	Need	% Ranked #1	Rank	Need	% Ranked #1
1	Finding housing	25.0	1	Finding housing	23.5
2	Mental wellness	20.6	2	Mental wellness	22.1
3	Improving spiritual well-being	13.2	3	Improving spiritual well-being	16.2
4.5	Finding work	11.8	4	Finding work	14.7
4.5	Combatting racism	11.8	5.5	Getting benefits	7.4
6.5	Getting benefits	7.4	5.5	Combatting racism	7.4
6.5	Improving relationships with others	7.4	7	Accessing quality health care	5.9
8	Accessing quality health care	5.9	8	Improving relationships with others	2.9

individual (mental and spiritual well-being) and structural (access to quality health care and benefits) determinants of mental health.

Our community engagement process and Delphi findings affected HNI design and implementation. Conference results were shared with DMH leadership, including the director and DMH staff overseeing HNI, some of whom participated in the Delphi exercise. To illustrate the impact on HNI design and implementation, one of the HNI pilot sites in Hollywood focuses specifically on the homeless in collaboration with LA Care, the Los Angeles Medicaid insurance plan, and the LAC Department of Health Services. The HNI/CPIC leadership is also working with housing authorities and faith-based mental health programs throughout the county to explore mutually beneficial partnering options. Finally, CPIC leaders are engaged in supporting HNI goals of services coordination to improve care access/quality across county agencies by actively participating in discussions on the potential restructuring of LAC health services agencies to meet mandates for Accountable Care Communities[26] and Medicaid Behavioral Health Home.[27] In particular, CPIC leaders contributed to the discussion of incentives to support collaborations across historically siloed sectors to improve outcomes through evidence-based integration strategies, such as depression collaborative care, while addressing social determinants of health, such as housing and employment.

Although sensitive to the analytic approach and limited to the perspective of conference attendees, the vast majority of whom have participated in previous community-wide initiatives, our findings illustrate the importance of addressing housing needs of depressed individuals, while paying attention to their social, spiritual, and health care access needs. Therefore, we recommend that new policies designed to address depression in under-resourced communities account for social, spiritual, economic, and political factors. We also suggest that a successful planning and implementation of a depression health care agenda may require engagement around social determinants of mental health to generate community buy-in. We recommend that community members, academics, and policymakers consider using the Delphi-based method described in this paper to inform the design and implementation of evidence-based policy initiatives. If carefully designed to account for community priorities and implemented in a partnered manner, such initiatives are likely to be more relevant to communities' needs and have a strong potential to positively affect the lives of a large number of individuals.

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REFERENCES

1. Kessler RC, Berglund P, Demler O, et al. The epidemiology of major depressive disorder: results from the National Comorbidity Survey Replication (NCS-R). JAMA. 2003;289(23):3095–105.

2. Kessler RC, Berglund P, Demler O, et al. Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the National Comorbidity Survey Replication. Arch Gen Psychiatry. 2005;62(6):593–602.

3. McGee RE, Thompson NJ. Unemployment and depression among emerging adults in 12 states, Behavioral Risk Factor Surveillance System, 2010. Prev Chronic Dis. 2015;12(E38):1–11.

4. Jackson-Triche M, Wells KB, Minnium K. Beating depression: The journey to hope. New York: McGraw-Hill; 2002.

5. Muntaner C, Eaton WW, Miech R, et al. Socioeconomic position and major mental disorders. Epidemiol Rev. 2004; 26(1):53–62.

6. Thota AB, Sipe TA, Byard GJ, et al. Collaborative care to improve the management of depressive disorders: A community guide systematic review and meta-analysis. Am J Prev Med. 2012;42(5):525–38.

7. Gilbody S, Bower P, Fletcher J, et al. Collaborative care for depression: A cumulative meta-analysis and review of longer-term outcomes. Arch Intern Med. 2006;166(21):2314.

8. Agency for Healthcare Research and Quality. National Healthcare Disparities Report, 2013. Rockville (MD): Agency for Healthcare Research and Quality; 2014.

9. Galea S, Vlahov D. Social determinants and the health of drug users: socioeconomic status, homelessness, and incarceration. Public Health Rep. 2002;117(Suppl 1):S135.

10. Jané-Llopis E, Anderson P, European Commission Health Consumer Protection. Mental health promotion and mental disorder prevention across European Member States: A collection of country stories. European Communities; Luxembourg. 2006.

11. Marmot MG, Wilkinson RG. Social determinants of health. New York: Oxford University Press; 2006.

12. Patel V, Lund C, Hatherill S, et al. Social determinants of mental disorders. Priority public health conditions: from learning to action on social determinants of health. Geneva: World Health Organization; 2009.

13. Wilkinson RG, Marmot MG. Social determinants of health: The solid facts. Geneva: World Health Organization; 2003.

14. Khodyakov D, Mendel P, Dixon E, et al. Community Partners in Care: Leveraging community diversity to improve depression care for underserved populations. Int J Divers Organ Communities Nations. 2009;9(2):167–82.

15. Khodyakov D, Sharif MZ, Dixon E, et al. An implementation evaluation of the community engagement and planning intervention in the CPIC depression care improvement trial. Community Ment Health J. 2014;50(3):312–24.

16. Wells K, 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):1268–78.

17. 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 of community engagement versus technical assistance in depression care. Ann Intern Med. 2014;161(10 Suppl):S23-S34.

18. County of Los Angeles. Strategic plan. Los Angeles (CA): County of Los Angeles; 2014.

19. Corbie-Smith G. The continuing legacy of the Tuskegee Syphilis Study: Considerations for clinical investigation. Am J Med Sci. 1999;317(1):5–8.

20. Bromley E, Mikesell L, Jones F, et al. From subject to participant: Ethics and the evolving role of community in health research. Am J Public Health. 2015;105(5):900–8.

21. Khodyakov D, Pulido E, Ramos A, et al. Community-partnered research conference model: The experience of Community Partners In Care study. Prog Community Health Partnersh. 2014;8(1):83–97.

22. Mendel P, Ngo VK, Dixon E, et al. Partnered evaluation of a community engagement intervention: Use of a kickoff conference in a randomized trial for depression care improvement in underserved communities. Ethn Dis. 2011;21(Summer):S1–78-S71–88.

23. Schoeman ME, Mahajan V. Using the Delphi method to assess community health needs. Technological Forecasting and Social Change. 1977;10(2):203–210.

24. Schopper D, Ammon C, Ronchi A, et al. When providers and community leaders define health priorities: the results of a Delphi survey in the canton of Geneva. Soc Sci Med. 2000;51(3):335–42.

25. Themba MN, Minkler M. Influencing policy through community based participatory research. In: Minkler M, Wallerstein N, editors. Community-based participatory research for health. San Francisco (CA): Jossey-Bass; 2003. p. 349–70.

26. Hughes LS, Peltz A, Conway PH. State innovation model initiative: A state-led approach to accelerating health care system transformation. JAMA. 2015;313(13):1317–8.

27. Bao Y, Casalino LP, Pincus HA. Behavioral health and health care reform models: patient-centered medical home, health home, and accountable care organization. J Behav Health Serv Res. 2013;40(1):121–32.