Strategies To Empower Communities To Reduce Health Disparities

Beti Thompson [professor],
Cancer Prevention Program at the Fred Hutchinson Cancer Research Center, in Seattle, Washington

Yamile Molina [postdoctoral research fellow],
Cancer Prevention Program, Fred Hutchinson Cancer

Kasisomayajula Viswanath [associate professor of popular sciences],
Department of Medical Oncology, at the Dana-Farber Cancer Institute, and an associate professor of human development and health at the Harvard T. H. Chan School of Public Health, both in Boston, Massachusetts

Richard Warnecke [professor emeritus], and
Health Policy Center, University of Illinois at Chicago

Michael L. Prelip [professor of community health sciences]
Fielding School of Public Health at the University of California, Los Angeles

Abstract

Community-based participatory research is a promising approach to reducing health disparities. It empowers individuals and communities to become the major players in solving their own health problems. We discuss the use of community-based participatory research and other strategies to enhance empowerment. We also discuss projects from the Centers for Population Health and Health Disparities that have empowered communities to achieve positive health outcomes aimed at reducing disparities. We offer recommendations to policy makers for involving residents in efforts to achieve health equity.

Health disparities continue to be a vexing problem in the United States, and the issue has long been a major focus of policy and research. The government's Healthy People 2000, 2010, and 2020 initiatives have aimed to reduce health disparities,[1] eliminate disparities,[2] and achieve health equity,[3] respectively. But despite concerted efforts, disparities and inequities persist.[4]

Researchers have recognized the futility of trying to change communities affected by health disparities by intervening at the individual level. A different approach, community-based participatory research, is based on working with communities. By involving people in identifying and defining their own health problems, this approach is most likely to develop sustainable solutions that work for both individuals and communities. It has been the focus of a growing body of literature.[5–7]

Community-based participatory research is based on collaboration between and participation by community members, representatives of community-based organizations, and researchers to achieve health equity through social action.[8] The approach involves a long-term partnership that is focused on a local health issue and involves co-learning, capacity building, shared decision making, mutual ownership of research findings, and dissemination of results.[6] It increases the relevance of the research to community members, balances power among the partners, and helps translate research into policy and practice.[6] It also helps identify community assets on which to build interventions, and it facilitates the exchange of knowledge between researchers and community members.[5]

The approach empowers individuals and communities as a whole to address their own health issues.[9–13] Empowerment can originate from outside the community (for example, from a researcher, community organizer, or outside supporter) or inside it.[10–12,14]

In this article we discuss how community empowerment methods have been and can be used to reduce disparities, with examples from some of the projects of the Centers for Population Health and Health Disparities program. We also discuss strategies that policy makers can use to empower communities.

Understanding Empowerment

Power generally refers to unequal relationships among people and the ability of some to influence the behavior of others;[15] power is often not balanced among diverse individuals in a community.[16] In a review of the effectiveness of empowerment to improve health and reduce health disparities, the World Health Organization concluded that empowerment can lead to better health outcomes.[11] It can help communities and individuals develop opportunities, capacities, and tools that benefit them, and it can ensure that communities can mobilize targeted populations to obtain needed health resources by fostering awareness of a given problem.[17] It can also ensure that communities have tools to use in advocating for their members' access to prevention, screening, and treatment. Empowerment often refers to either individual or collective power, but in this article we focus on collective power that can be engendered in the community.

Community empowerment is a process. First, power analyses should be conducted to understand the power relationships in a community and possibly reveal innovative strategies for equalizing power in the community.[18,19] Outlining the distribution of power in a community, referred to as "mapping," involves describing in depth which individuals and groups have the power to make decisions in a community. These analyses inform the process of strategic relationship building.[20]

Next, the current policies and systemic factors that govern community health-related issues, and what groups are responsible for the adoption of the policies, should be identified. Agents of empowerment should also be identified. They can be external to the community (such as community organizers and academic researchers skilled in working with community members) or members of the community (such as community health workers and pastors in churches serving the poor).

It may be difficult to empower communities to address health disparities if community partners appear less concerned than researchers and policy makers with system changes, such as health system or legal system reform. The underserved are likely to be more worried about addressing the social determinants of health, including finding safe housing, feeding a family, or having a job, than about preventing cancer.[21,22] This should not be construed as a lack of interest in reforming inequitable systems on the part of the underserved, however. Many of these people recognize that discrimination and unequal power are the cause of social inequities that lead to unfavorable social determinants, such as low-quality housing. Thus, it is important to empower communities through interventions that target the social determinants of health.[21]

Researchers working with underserved communities are likely to be most successful in empowering the community not only when the availability of health resources improves, but also when norms supporting those changes emerge and become "policy" at the community level (for instance, when it becomes the norm to wear a seat belt or get seasonal flu shots).

Below we offer three examples of the use of community-based participatory research and community empowerment to address health disparities.

Empowerment At Work In Communities

A MEDIA INTERVENTION

In 2010 the Harvard T. H. Chan School of Public Health's Center for Population Health and Health Disparities initiated a project to modify public views of tobacco use in a small Massachusetts town. The researchers wished to generate support in the local media for addressing health inequities in general and related to tobacco use in particular. Their approach was based on the assumption that the media play an important role in identifying the causes of and potential solutions for health inequities. The researchers felt that changing the public health agenda to support policies and programs to address health inequities was necessary; they also believed that such a change required mobilizing support from the powerful social and institutional forces in the community.

Using a "community reconnaissance method" to identify major actors in the community who were perceived to play an important role in addressing health, the Harvard center examined the relationship among the actors.[23] This method is designed to identify not only policy makers, but also the people who influence policy makers. In the Harvard project, in-depth semistructured interviews were conducted with policy makers who were nominated by members of the community as influential on health issues, to shed light on how power was distributed in the community.

The reconnaissance approach yielded a rich and detailed picture of leaders in different power positions in the community, the interactions among them, and their views on health inequities and how to address them. The analysis guided the development of the media intervention, which was intended to change the public health agenda by ensuring that greater attention was paid to the social determinants of health in news coverage. The intervention

consisted of workshops at which members of the media received education about the social determinants of health.

The Harvard study is ongoing and has not yet provided evidence that the media intervention has changed the community's awareness that poor health is not caused solely by individual factors. However, the first necessary steps for that change to occur have been taken.

REDUCING BREAST CANCER MORTALITY

A history of collaborative research with community partners was key to the success of the Center for Population Health and Health Disparities at the University of Illinois at Chicago.[24,25] In 1995, mortality from breast cancer among non-Hispanic black women in Chicago was 98 percent higher than among white women. Breast cancer mortality has decreased for white women but has remained almost unchanged for black women since the 1990s. In 2008, in response to these data, researchers at the University of Illinois at Chicago, working with the Sinai Urban Health Institute, formed the Metropolitan Chicago Breast Cancer Task Force to address the disparity. They worked with community residents and groups, assembling a task force that grew to include a hundred public advocacy groups, researchers, and breast cancer experts.[24]

The task force produced a report[26] containing specific evidence-based recommendations that culminated in the Reducing Breast Cancer Disparities Act of 2009. The act provided increased Medicaid reimbursement for digital mammograms, expanded Medicaid coverage for mammography, eliminated copayments and deductibles for mammograms, and created a pilot program to help women covered by Medicaid navigate health services. Other provisions established a Medicaid patient rescreening reminder system, exercised the option of a state panel to establish quality standards for mammography, developed a Medicaid reimbursement rate for mammography, and established a Medicaid "pay for performance" bonus for primary care providers who refer patients to mammography.

When a subsequent amendment to the legislation required that the increased Medicaid reimbursement rates be tied to submission of mammography quality data by mammography facilities and radiologists, the task force was contracted by Medicaid to implement a mammography quality surveillance program. In 2014 it published its report on Illinois, noting a 35 percent reduction in breast cancer mortality among black women from 2009 to 2012.[26] Recent reports indicate that the task force contributed to a significant reduction in the mortality disparity between white women and women of color, from 63 percent in 2007 to 40 percent in 2014.[27]

EMPOWERING TEENS TO IMPROVE FOOD ENVIRONMENTS

In East Los Angeles and Boyle Heights—predominantly low-income Latino communities in Los Angeles, California—the quality of the local food environment became a key concern of community members, neighborhood nonprofit agencies, and staff members of the local public health department because of the dearth of availability of healthy food. Researchers built on existing relationships within the community to develop a multilevel, community-based participatory research project to convert small neighborhood corner stores with

unhealthy food options to stores that offered healthy food options and by mounting a social marketing and education campaign.[28]

East Los Angeles and Boyle Heights residents were engaged in both program and research activities. Teens from area schools were trained in store conversion and social marketing, thus empowering them to change their own food environment. The approach was quickly accepted by community-based organizations, whose members were interested in creating opportunities for local youths to become advocates for the community as well as to develop leadership skills and learn about potential health-related careers.

Early in the project it became evident that the topic of nutrition did not resonate with teens in these communities. Messages about healthy eating (such as the food pyramid and the US Department of Agriculture's MyPlate campaign) had been heard repeatedly, and the teens seemed to have tuned them out. However, when the issue was presented as a food justice and power inequity issue, the youths became highly interested in the topic of food deserts (areas where healthy food options are lacking) and food swamps (areas where unhealthy food options abound). They related more to food environment issues and how this affected poor dietary behavior than they did to individual factors associated with dietary behavior.

Working with two local high schools, the YMCA, and an arts and civic engagement organization, the Center for Population Health and Health Disparities established a semester-long elective course focused on food environments, food justice, health disparities, media literacy, arts for social change, social advocacy skills, corner store conversions, social marketing, and nutrition, as a means of creating opportunities for youth development and youth empowerment. The classes provided the students with the skills to do something about the problem in their community. The teens became the face and voice of the project: They were responsible for developing the brand of the project (Proyecto Mercado-FRESCO, or fresh market project), creating and disseminating social marketing materials, remodeling and restocking corner stores, presenting information and performing skits (written by the teens) at key community and school events, and meeting with community leaders. Through their efforts, they showed the community, including their teachers and parents, and themselves that they could have an impact on the social determinants of health and social norms (related to healthy eating) that affected them and their community. The researchers successfully converted two small corner stores that provided primarily unhealthy foods to stores that included a variety of healthy foods, including fresh fruit and vegetables that were strategically placed at the stores' entrances.

Discussion

The Centers for Population Health and Health Disparities projects described above took a variety of approaches to community empowerment. These included understanding the roots of power and how it was manifested in the Harvard center's project, engaging the community in creating recommendations to address black-white differences in breast cancer rates in Chicago, and empowering teens in Los Angeles to fight for food equity by framing it as a social justice issue. Community partnerships have required university-based researchers to explore and consider new approaches to understanding community empowerment.

Paramount among these approaches is understanding and building on the assets that communities bring to research projects.

In a town in Massachusetts, understanding community power was key to developing an intervention intended to change how the media report on health. The University of Illinois at Chicago also worked to understand local power issues to develop a citizen-led partnership to address breast cancer mortality. The resulting breast cancer task force was instrumental in changing the policy agenda and in revising the policy when gaps between black and white women were noted in breast cancer screening.

The examples demonstrate one way of measuring empowerment: through changes in the relationships among people. They illustrate that changes occurred in the communities that affected the ability of underserved individuals to take advantage of health services. This has the potential to change the environment within which health disparities occur. As the examples show, a community-based participatory research approach can redistribute power and subsequently change health behavior.

Previous studies confirm that community empowerment can reduce health disparities. In the Transgender Community Health Project, aimed at assessing HIV/AIDS risk among transgender people in San Francisco, empowerment allowed the community to define and work toward a solution that met its own needs, regardless of the resources required to make it happen.[5] As a result of the project, policy makers awarded funding for identifying HIV/ AIDS in transgender individuals.[5] A study of youth suicide in First Nations communities (indigenous populations) in Canada found a strong inverse correlation between empowerment of the communities and the rate of youth suicide.[29] Similarly, a study of HIV prevention among sex workers in Calcutta, India, found that empowerment to make their own decisions on which prophylactic activities to pursue led to a significant decrease in HIV prevalence among the sex workers compared to those in other Indian cities, and condom use among Calcutta sex workers increased from 3 percent in 1992 to 90 percent in 1999.[30]

Improving the health outcomes of communities through community empowerment relies on ongoing trust and relationship building between the community and researchers. Although it is important to begin initiatives at the local level to engage community members and secure their buy-in, making differences in the health of a community often requires policy decisions at the local, state, or national levels. Community-based participatory research efforts to improve community health outcomes must simultaneously develop and maintain partnerships among key stakeholders (individuals, businesses, media, and others) at different levels to influence policies to improve health.

Policy makers must recognize and facilitate empowerment at a variety of levels. This can be done by involving community members and the underserved in the initiation and implementation of policy, as well as by relying on people who hold more traditional power. Decision making should not be left to policy makers alone: It is their responsibility, to the underserved and to the communities in which they work, to achieve shared policy making. Involving policy makers in the empowerment of underserved populations has the potential to reduce health disparities.

Conclusion

If health disparities are to be reduced or eliminated, the playing field must be leveled. One way to do that is to empower communities so that everyone has access to the national, regional, and local assets that equalize available opportunities. It is not always easy to empower community members and the underserved, but without full participation in a healthful society, a sizable portion of the US population will be excluded from good health. Empowered communities can work toward the common goal of reducing and eventually eliminating health inequities.

Acknowledgments

NOTES

1. National Center for Health Statistics. Hyattsville (MD): NCHS; 2001. Healthy People 2000: final review [Internet]. Available from: http://www.cdc.gov/nchs/data/hp2000/hp2k01.pdf [cited 2016 Jun 24]

2. National Center for Health Statistics. Hyattsville (MD): NCHS; 2012. Healthy People 2010: final review [Internet]. Available from: http://www.cdc.gov/nchs/data/hpdata2010/hp2010_final_review.pdf [cited 2016 Jun 28]

3. Washington (DC): Department of Health and Human Services; Introducing Healthy People 2020 [Internet]. HealthyPeople.gov. last updated 2016 Jun 28; Available from: http://www.healthypeople.gov/2020/About-Healthy-People [cited 2016 Jun 28]

4. Institute of Medicine. Unequal treatment: confronting racial and ethnic disparities in health care. Washington (DC): National Academies Press; 2003.

5. Minkler, M., Wallerstein, N., editors. Community-based participatory research for health: from process to outcomes. 2. San Francisco (CA): Jossey-Bass; 2008.

6. Israel, BA.Eng, E.Schul, AJ., Parker, E., editors. Methods in community-based participatory research for health. San Francisco (CA): Jossey-Bass; 2005.

7. Minkler M, Vásquez VB, Warner JR, Steussey H, Facente S. Sowing the seeds for sustainable change: a community-based participatory research partnership for health promotion in Indiana, USA and its aftermath. Health Promot Int. 2006; 21(4):293–300. [PubMed: 16873393]

8. Viswanathan, M., Ammerman, A., Eng, E., Gartlehner, G., Lohr, K., Griffith, D., et al. Rockville (MD): Agency for Healthcare Research and Quality; 2004 Jul. Community-based participatory research: assessing the evidence [Internet]. (AHRQ Publication No. 04-E022-2). Available from: http://archive.ahrq.gov/downloads/pub/evidence/pdf/cbpr/cbpr.pdf [cited 2016 Jun 24]

9. Kennedy S, Hardiker N, Staniland K. Empowerment as an essential ingredient in the clinical environment: a review of the literature. Nurse Educ Today. 2015; 35(3):487–92. [PubMed: 25542857]

10. Laverack G. Improving health outcomes through community empowerment: a review of the literature. J Health Popul Nutr. 2006; 24(1):113–20. [PubMed: 16796158]

11. Wallerstein, N. Copenhagen: World Health Organization Regional Office for Europe; 2006 Feb. What is the evidence on effectiveness of empowerment to improve health? [Internet]. (Health Evidence Network Report). Available from: http://www.euro.who.int/__data/assets/pdf_file/0010/74656/E88086.pdf [cited 2016 Jun 24]

12. Wiggins N. Popular education for health promotion and community empowerment: a review of the literature. Health Promot Int. 2012; 27(3):356–71. [PubMed: 21835843]

13. Cargo M, Mercer SL. The value and challenges of participatory research: strengthening its practice. Annu Rev Public Health. 2008; 29:325–50. [PubMed: 18173388]

14. Dahl RA. The concept of power. Behav Sci. 1957; 2(3):201–15.

15. Mulder, M. The daily power game. Leiden: Martinus Nijhoff Social Sciences Division; 1977.

16. French, JRP., Jr, Raven, B. The bases of social power. In: Shafritz, JM.Ott, JS., Jang, YS., editors. Classics of organization theory. 8. Boston (MA): Cengage Learning; 2016. p. 251-60.

17. Rissel C. Empowerment: the holy grail of health promotion? Health Promot Int. 1994; 9(1):39–47.

18. Brugha R, Varvasovszky Z. Stakeholder analysis: a review. Health Policy Plan. 2000; 15(3):239–46. [PubMed: 11012397]

19. Mayers, J. Stakeholder power analysis [Internet]. London: International Institute for Environment and Development; 2005 Mar. Available from: http://www.policy-powertools.org/Tools/Understanding/docs/stakeholder_power_tool_english.pdf [cited 2016 Jun 24]

20. Treadway D, Breland J, Williams L, Cho J, Yang J, Ferris G. Social influence and interpersonal power in organizations: roles of performance and political skill in two studies. J Manage. 2013; 39(6):1529–53.

21. Braveman P, Egerter S, Williams D. The social determinants of health: coming of age. Annu Rev Public Health. 2011; 32:391–8.

22. Golob MI, Giles AR. Challenging and transforming power relations within community-based participation research: the promise of a Foucauldian analysis. Qualitative Research in Sport, Exercise, and Health. 2013; 5:356–72.

23. Nix HL, Seerley NR. Community reconnaisance method: a synthesis of functions. J Community Dev Soc. 1971; 2(2):62–9.

24. Ansel D, Grabler P, Whitman S, Ferrans C, Burgess-Bishop J, Murray L. A community effort to reduce the black-white breast cancer mortality disparity in Chicago. Cancer Causes Control. 2009; 20(9):1661–8.

25. Metropolitan Chicago Breast Cancer Task Force. Chicago (IL): The Task Force; 2007 Oct. Improving quality and reducing disparities in breast cancer mortality in metropolitan Chicago [Internet]. Available from: http://www.chicagobreastcancer.org/site/files/904/101098/352646/483158/Task_Force_Report,_October_2007.pdf [cited 2016 Jun 27]

26. Metropolitan Chicago Breast Cancer Task Force. Chicago (IL): The Task Force; 2014 Oct 30. Beyond October how far have we come? Breast cancer disparities: improving access and quality of breast health services in Chicago [Internet]. Available from: http://www.chicagobreastcancer.org/site/files/904/93199/353837/718237/State_of_Breast_Cancer_Disparties_Report_Final_11.pdf [cited 2016 Jun 27]

27. Rauscher GH, Murphy AM, Orsi JM, Dupuy DM, Grabler PM, Weldon CB. Beyond MQSA: measuring the quality of breast cancer screening programs. AJR Am J Roentgenol. 2014; 202(1):145–51. [PubMed: 24261339]

28. Paskett E, Thompson B, Ammerman AS, Ortega AN, Marsteller J, Richardson D. Multilevel interventions to address health disparities show promise in improving population health. Health Aff (Millwood). 2016; 35(8):1429–34. [PubMed: 27503968]

29. Chandler MJ, Lalonde C. Cultural continuity as a hedge against suicide in Canada's First Nations. Transcult Psychiatry. 1998; 35(2):191–219.

30. Jana S, Basu I, Rotheram-Borus MJ, Newman PA. The Sonagachi Project: a sustainable community intervention program. AIDS Educ Prev. 2004; 16(5):405–14. [PubMed: 15491952]