

Virtual Mentor

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FROM THE EDITOR

Making House Calls on the Community

Justice. As physicians, we hardly ever think of ourselves as arbiters of such a thing—individual bodies, after all, are not seats of justice or injustice. Yet its pursuit is one reason why many of us chose to learn the art of medicine. The social and medical ills that bleed into one another are too often encountered by communities that are denied access to healthy living. This intersection of social and medical ills is precisely the focus of community-based participatory research (CBPR). While not a panacea, this crucial intervention is geared not only toward uncovering and understanding disparities, but also toward empowering the very people made invisible by them; with CBPR, everyone has a seat at the table. Dr. Meredith Minkler, one of the pioneers of CBPR, historicizes our understanding of the field by describing its roots as

most deeply grounded in the more revolutionary approaches to research that emerged, often independently from one another, from work with oppressed communities in South America, Asia, and Africa in the 1970s.... [D]eveloping countries' scholars developed their alternative approaches to inquiry as a direct counter to the often "colonizing" nature of research to which oppressed communities were subjected, with feminist and postcolonialist scholars adding further conceptual richness [1].

In the United States, communities of color and low-income populations are especially vulnerable to hypertension, kidney disease, diabetes, environmental morbidities, cancer, and, of course, heart disease—every health professional can rattle off the list of “who’s who” in the game of At Risk. Though efforts to treat these comorbidities must continue, the socioeconomic contributors to their pathogenesis demand our urgent attention as well. Social context and its effects on health are not solely the responsibility of sociologists, public health scientists, and anthropologists. It is also the responsibility medical students, residents, and physicians to see not only the patients sitting in front of us, but the stories they bring with them into our office.

In some ways, CBPR is the spiritual heir of the practice of making house calls. These visits afforded the physician a closer look at the patient’s environment, family dynamics, and diet; the diagnostic lens was wider than in the now-typical “snapshot” interaction. CBPR affords physicians the opportunity to restore that practice and see the motion-picture context that gives meaning to the still frame frozen in a patient’s chart.

Perhaps the time has come for us to make “house calls” on the community. Around the country, CBPR partnerships are in action. At the Detroit Urban Research Center, physicians and their partners are working to relieve the burden asthma has placed on inner-city Michigan communities and spearheading various interventions to improve the incidence of diabetes and kidney disease. Morehouse School of Medicine is well known for its CBPR programs, especially the Community Based Research Cancer Unit. One of the unit’s foci is eliminating racial disparities in breast and cervical cancer. There has also been a promising increase in funding for CBPR. In 2002, the prestigious Robert Wood Johnson Foundation expanded its Clinical Scholars Program to include CBPR because the organization saw that

no longer can physician-scientists design research studies in a vacuum and expect that subjects will participate and embrace such findings as research. It is clear that in the 21st century, the public must have input into the conceptualization, design and execution of research studies with the medical scientists [2].]

There *is* no panacea for health disparities, but as researchers we know that every step in the methodological process vibrates with the sobering potential to change lives. Therein lies the impetus for this issue of *Virtual Mentor*.

Great care must be taken when any human subject is involved in research, but especially when those subjects are part of communities made vulnerable by historical and contemporary marginalization. The ethical concerns specific to cases outside the boundaries of conventional clinical research are discussed in this month’s clinical case commentaries. In the first case, Carla C. Keirns, MD, PhD, MSc, clinical ethics director of the history of medicine program at Stony Brook University, and a former Robert Wood Johnson Clinical Scholar, and Florence Thicklin, a community-engaged research consultant and community partner with the University of Chicago’s South Side Health and Vitality Studies, offer their guidance about the balancing act demanded of a neighbor and a physician-researcher.

Consuelo H. Wilkins, MD, MSCI, director of CARE in Our Community and associate professor at Washington University School Medicine, comments on the dilemma physician-scientists can find themselves in when community members become upset about the results of CBPR. How should practitioners negotiate the disclosure of results, particularly when they threaten to paint a community in a less-than-positive light? In this particular case, CBPR uncovers a high rate of sexually transmitted diseases in the community, including HIV/AIDS. Lisa K. Fitzpatrick, MD, MPH, professor of medicine at Howard University, tackles the topic of missed HIV diagnosis among older adults in this month’s clinical pearl.

With the media covering the suicides of several gay teens linked to bullying and societal pressure, our third case is unfortunately quite timely. Oftentimes, community partnerships involve religious organizations, due to their steadfastness and membership base in communities. Johns Hopkins’ Jessie Kimbrough-Sugick, MD, MPH, Jessica Holzer, MA, and Eric B. Bass, MD, MPH, editor in chief of *Progress*

in Community Health Partnerships, provide guidance for health professionals about the nuances of framing the research topic in terms acceptable to socially conservative community partners.

As CBPR gains traction, questions arise about how it fits into the traditional research system. As Tim Hotze, a senior research assistant at the American Medical Association's Institute for Ethics, writes, the differences between the ethical underpinnings of traditional research and those of CBPR are becoming better understood, but the means for accommodating CBPR's special ethical demands remain to be worked out. In his journal discussion, Andrew Plunk, MPH, reviews an article that explores the ways in which institutional review board (IRB) approval forms privilege traditional research methods, which can hinder the ideals of CBPR and even harm community participants, and how changes in form language can ensure the quality of community-based research proposals. Similarly, Nicolette I. Teufel-Shone, PhD, a professor with joint appointments in both anthropology and public health at the University of Arizona, examines the ways CBPR achievements are incompatible with those considered important to academic career-building and tenure review.

This month's health law piece by Robyn L. Sterling, JD, MPH, underscores the importance of adhering to community-based research ethics, especially in the face of research pressures to do otherwise. She looks at the experience of the Havasupai Tribe, whose genetic material was used for research other than that for which they had consented, causing damage to the tribe and its relationship with Arizona State University's researchers. A complementary excerpt from the American Medical Association's *Code of Medical Ethics*, "Safeguards in the Use of DNA Databanks in Genomic Research," contains provisions designed to prevent just this kind of misuse of data and mistreatment of research participants.

The crux of CBPR hinges on the parameters of our definitions of "community," and how we create the borders of our own and our research subjects' identities. This is an enormously volatile concept because it threatens to shift the community autonomy that CBPR aims to empower back into the hands of outsiders, in the guise of well-meaning CBPR practitioners. In the medicine and society section, Karla F.C. Holloway, PhD, MLS, of Duke University, forces us to look beneath our white coats at the prejudices we may not even be aware of even as we perpetuate them.

There is no hiding from the progress that still needs to be made. We must take part in cultivating the transparency and levers for advocacy that CBPR offers. We must ask our policymakers to partner with us to create legislation congruent with a community-based approach to research. We must refuse to stay within the cozy confines of our comfort zones or treat patients' bodies as separate from their lives. And most importantly, we must follow the lead of community members when we work in partnership, instead of assuming that we can diagnose and treat families, neighborhoods, and ethnic groups from afar.

References

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