Determining What We Stand for Will Guide What We Do: Community Priorities, Ethical Research Paradigms, and Research With Vulnerable Populations

Prisoners, ex-offenders, and the communities they belong to constitute a distinct and highly vulnerable population, and research must be sensitive to their priorities. In light of recent suggestions that scientific experimentation involving prisoners be reconsidered, community-based participatory research can be a valuable tool for determining the immediate concerns of prisoners, such as the receipt of high-quality and dignified health care inside and outside prisons. In building research agendas, more must be done to ensure the participation of communities affected by the resulting policies. (Am J Public Health. 2009; 99:201–204. doi:10.2105/AJPH.2008.125617)

GIVEN RECENT PROPOSALS to reexamine federal regulations pertaining to human experimentation in prisons,1–4 it is important that more be done to ensure that the viewpoints and life experiences of prisoners, ex-offenders, and their communities be considered. There has been recent debate about what constitutes ethical research in prisons and about the possible expansion of the scope of what is allowable. These questions arise because biomedical researchers are having difficulty in recruiting volunteers for clinical trials5 in the United States and because a number of private companies are increasingly seeking volunteers in other countries in which the costs of these experiments are less expensive, protocols are less complex, and compliance standards are less onerous.6–9

Some US researchers suggest that current regulations guiding prison research may be too strict and outdated,1,4 and arguments have been made in favor of reassessing the current norms.3,4 It has been noted, for example, that with the existence of institutional research boards, prisoners may actually benefit from this research if protocols are strengthened.1,3,4 At least one researcher has argued that prisoners have a constitutional right to choose to participate in a study, clinical or otherwise.7 Other work has suggested that prisoners ought to have the same access to experimental drugs as people who are not in prison and that there are ways to erect safeguards to ensure that the abuses committed in the past are not repeated.2–4

We argue that until the question of adequate health care for prisoners is resolved, human experimentation should not be allowed. Why are so many people from low-income, minority communities incarcerated? Why do these populations appear to be a convenient and natural source for social research? And, given that prisons do exist, why is it that a stronger focus is not placed on appropriate and dignified care for confined populations, such as those inside prisons as well as for ex-offenders and their communities? Why is not greater precedence being given to finding the best methods for ensuring one single standard for all?

We know, for example, that prisoners tend to be sicker than the rest of the population, bearing significantly higher rates of infectious diseases such as hepatitis C, tuberculosis, and HIV as well as chronic conditions including asthma, hypertension, diabetes, and oral illnesses. High rates of mental illness are also prevalent,9–12 as well as the co-occurrence of substance abuse and mental illness. How these illnesses are treated in prison, and how much care is provided to ex-offenders after they leave prison, have direct implications for the co-occurrence of substance abuse and mental illness. How these illnesses are treated in prison, and how much care is provided to ex-offenders after they leave prison, have direct implications for whether an ex-offender will reintegrate into society successfully.13

For research in prisons to be ethical, it must be interested in upholding prisoners’ constitutional right to appropriate quality care while in prison and ensuring a stronger and more effective safety net for them when they return home. It must focus first on ensuring that the health of all is protected. It must ask what safeguards are in place for those who have engaged in clinical trials while in prison should they later become ill or infected.

COMMUNITIES AND PRISON POPULATIONS

In 2007, the prison population of the United States stood at nearly 2.3 million.6,14 This figure has quadrupled in the past 30 years,6 caused in part by strict sentencing policies for drug offenses. During this period, African American men were arrested, convicted, and incarcerated at higher rates and for longer periods than were other racial and ethnic groups.12 In the year 2000, Latinos in the United States made up 20% of the prison population.15 Poor communities of color are particularly affected by this high incarceration rate on numerous levels, with women and children losing the active presence of partners and fathers and their income and support.15,16 Women are presently the fastest-growing segment of the US prison population.17 Similar to male prisoners, female prisoners tend to have lower incomes, lower educational levels, and higher rates of mental illness and substance abuse than does the nonprison population.17,18 Women also often leave behind children and families.

For many ex-offenders coming home, the resources are not there to
Research clearly shows that health conditions and access to quality care are especially substantial for ethnic and racial minorities, both in general and inside prisons, which house inmates mostly belonging to racial and ethnic minorities. The Eighth Amendment to the US Constitution prohibits “cruel and unusual punishments,” and although prisoners have a constitutional right to receive medical care, far too often its availability and quality are limited. The recent situation in California’s prison medical system, currently under federal receivership as a result of a number of prisoners who died of preventable causes, is one example of the challenges that prison health care providers are experiencing. Furthermore, the efforts of prison providers may be hampered as a result of poor policies, limited resources, and prison infrastructure.

The problem extends beyond prison walls. Many US communities—too often, communities of color—lack the bare minimum of health care. Should not research be concerned with the need for better health care for the most vulnerable communities, both inside and outside prisons?

**PATHWAYS TOWARD ETHICAL RESEARCH**

Community-based participatory research (CBPR) offers one pathway to ethical research that includes the perspectives of prisoners, ex-offenders, and their communities. CBPR is increasingly recognized as an approach that includes the voices, knowledge, leadership, and thinking of community members in research and decisionmaking. This marks an important epistemological shift toward greater appreciation of knowledge from untraditional sources, as well as an opportunity for hearing and including the real concerns of communities. In pursuing CBPR, we are also confronted with critical ethical questions regarding how to proceed equitably on the basis of principles and values of partnership and how to ensure that those engaged truly benefit from this process—not because of what has been given to them but because of what they, through their own agency, have determined is valuable and constructive for themselves.

Communities can be defined in a number of ways. There are geographical communities as well as communities based on common conditions of existence. Seen in this way, prisoners, ex-offenders, and the neighborhoods that they leave behind and return to may be viewed as a distinct, highly vulnerable community. In trying to engage this community as partners in research through CBPR, researchers must first ask what its priority concerns are. The answer is clear: quality and dignified care for both those in prison and those outside and the resources and infrastructure to help ex-offenders resume their lives when they come back home.

More must be done to ensure that prisoners, ex-offenders, and their communities have a say in building a research agenda that will affect them and the manner in which they and, ultimately, all live in this nation. A first step toward building a stronger base for CBPR would be to work directly with affected groups and ensure that their recommendations are upheld. We explore how some of the possible applications of CBPR may help to shed light on the current health status of vulnerable communities, both inside and outside of prisons.

**THE NEED TO IMPROVE HEALTH CARE**

The data on the need to improve access to health care and its quality for everyone in the nation, but particularly for vulnerable populations, are irrefutable. In one particularly strongly worded report, the Institute of Medicine noted, the US health care delivery system does not provide consistent, high-quality medical care to all people. Americans should be able to count on receiving care that meets their needs and is based on the best scientific knowledge—yet there is strong evidence that this frequently is not the case. Health care harms patients too frequently and routinely fails to deliver its potential benefits. Indeed, between the health care that we now have and the health care that we could have lies not just a gap, but a chasm.

In addition, research has shown how best to train public health practitioners and researchers to engage communities equitably. CBPR holds promise as a way of working with vulnerable communities as equal partners, particularly because it underscores the ethical responsibilities that the scientific community has toward the public. The National Institutes of Health has devoted attention to CBPR projects that seek to promote the
use of partnership approaches in studying and addressing health issues.27 These advances come at a time when there is increased recognition of the efficacy of community-driven approaches in health research, particularly where racial and ethnic disparities are concerned.27

**IMPROVING COMMUNITY RESEARCH AND HEALTH FOR ALL VULNERABLE POPULATIONS**

CBPR offers an important pathway toward enabling communities to tell their story from their perspective. Israel et al. define CBPR as

> A partnership approach to research that equitably involves, for example, community members, organizational representatives, and researchers in all aspects of the research process and in which all partners contribute expertise and share decisionmaking and ownership.27

Because it regards research as a collaborative process, CBPR offers opportunities for communities affected by social, economic, political, and environmental policies to be heard on equitable terms. This approach becomes particularly relevant for low-income communities—often communities of color—who have historic reasons to distrust research and researchers.27 As Israel et al. have said, CBPR offers the space to create a climate of "cultural humility" and "cultural safety."27 In the former, expertise is shared with the community in question; in the latter, the responsibility is on the researcher to ensure that community partners feel safe in the process.

Regarding prison research, CBPR may be an important vehicle for engaging affected communities on such pressing research questions as the following: What kinds of health care are prisoners receiving, and what kinds of chronic illnesses are they faced with in prison? How has the absence of appropriate care in prison contributed to ex-offenders’ health outside of prison? What aggregate impact is this having on their communities? How might communities help to shape the research agenda? How might both prisoners and their communities be prepared for prisoners’ return to these communities? What are the costs and benefits of clinical trials on entire communities? What happens to people who have undergone voluntary clinical trials in prison once they come home? Are there resources for follow-up care once they leave prison? What kinds of mechanisms might be developed to ensure that those who do undergo trials can deal with possible adverse reactions?

Research on the conditions in prison suggests that incarcerated people have no guarantee of health care when they leave prison.24 There is evidence that those who have undergone clinical trials in prison have little or no follow-up care for potential secondary effects after they are released.36 CBPR can further play a role here by bringing together those affected communities and prison health care providers to forge new and improved solutions.

**PROMISING PRACTICES**

The principles laid out in the 1979 Belmont Report, *Ethical Principles and Guidelines for the Protection of Human Subjects of Research,*37 continue to be relevant today, especially regarding research with vulnerable populations. Respect for persons, beneficence, and justice must still be considered touchstones that guide the work of ethical research. Through CBPR, respect for persons can be expanded to respect for communities, “do no harm” can be expanded to “do the right thing,” and community empowerment can be promoted.38 Finally, for there to be meaningful community collaboration and leadership in bringing about change, justice must be considered in terms of equitable access to decisionmaking and the impact of policies on the community.38

Of further concern is the need to acquire information based on the real-life experiences of communities. For at-risk populations targeted for clinical trials, participatory research practices must work consistently toward strengthening communities, building social capital for those within the communities, and developing relationships with others doing advocacy work in similar areas to ensure that community concerns are also weighed in the research process (C. Caceres, MD, PhD, Public Health and Administration Division, Universidad Cayetano Heredia, Lima, Peru, oral communication, April 2007). In this way, the issues that concern communities and the communities’ thoughts on these issues inform research and subsequent policies.

Recent work has demonstrated the efficacy of CBPR in working with people returning to their communities from prison.30,39 Beyond partnering with communities to inform city policies, some research designs have been able to uncover participants’ experiences and their perceptions regarding prison’s ability to prepare inmates for release and a return to the community.30 The short-term effects of this research have been the drafting of policies that, at a minimum, begin to reflect the concerns of those affected.30

Participatory research work in Miami, Florida, with men from the impoverished community of Overtown revealed concerns about time spent in prison and the need for better policies aimed at reintegration and support for community well-being.20 As this kind of research moves forward, providers of care must also be partners, because they too hold the keys for improved outcomes.

**CONCLUSIONS**

A recent report by a working group devoted to developing an action plan for prisoners reentering the community made two overarching recommendations: end the invisibility of prisoners and ex-offenders and end their isolation.40 CBPR can be an effective tool for ensuring that prisoners and ex-offenders have a say in policies that affect them and for preventing their being marginalized by policies that do not reflect their needs.

Regarding human experimentation in prisons, a number of questions remain unresolved that would benefit from community input. Why, for example, has the prison population been singled out for this experimentation? Historically, the federal government’s regulation of research involving vulnerable populations has also included nursing homes, hospitals, and mental institutions.41,42 Why is there no review of appropriate ethical regulations where these populations are concerned? In effect, why not consider the ethical concerns of all vulnerable populations? Why single out one particular group, one that is so clearly populated by ethnic and racial minorities?

In the final analysis, research can best contribute to the improvement of the health of...
vulnerable populations by stressing the ethics and the primary principles and practices that are the foundations of a civilized society. This would mean a concern for the immediate needs of the most marginalized, including access to health care and well-being. It would mean listening and giving fair time to those most affected. In the quest for knowledge and social evolution, determining what we stand for as a nation will guide what we do.

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