

ABSTRACT

Community-based participatory research (CBPR) promotes the idea that collaborative partnerships enable more equitable opportunities for community engagement, and more prominent roles for community partners in the ownership and control of project outcomes. The University of Oklahoma Community Networks Program (OUCNP) is a community-based participatory effort to reduce cancer health disparities in Native American and African American populations, and has created collaborative partnerships among diverse community partners including the historically All-Black towns of Oklahoma and two Oklahoma tribal nations. There are striking dissimilarities in collaborative capabilities among the community partners on this project. This article explores the implications of conducting CBPR projects with inequitable community partners, and how such partnerships are only truly collaborative once the infrastructural disparities that emerge within and among community partners are addressed.

KEY WORDS: CBPR, cancer control, African Americans, tribal nations, Oklahoma

INTRODUCTION

The National Cancer Institute awarded \$95 million in 2005 to 25 research institutions across the country to implement the Community Networks Program (CNP), a five-year project "with an emphasis on developing efficacious community-based participatory interventions to reduce cancer health disparities" (RFA-CA-05-012). Researchers at the University of Oklahoma and the University of Oklahoma Health Sciences Center received funds to develop the University of Oklahoma Community Networks Program (OUCNP). The OUCNP works to reduce cancer health disparities in Native American and African American populations in Oklahoma, and has created collaborative networks among university and state health institutions, health advocacy groups, an organization representing the historically All-Black towns of Oklahoma, and two tribal nations.

The specific African American and tribal community partners included on this project were identified on the basis of previous collaborative research relationships with project researchers. Additionally, the burden of cancer in Oklahoma, especially among African American and Native American populations, is significant. In general, African Americans have disproportionately higher incidence and mortality rates for many cancers and they experience higher risks for cancer because of lifestyle choices and barriers to appropriate cancer interventions. Cancer was also the second leading cause of death in 2003 among Native Americans in Oklahoma (Cobb and Paisano 1998; USDHHS 2000). The number of deaths associated with cancer among Native Americans aged 45 years and older

exceeds the next 3 leading causes of death (diabetes, unintentional injuries, chronic liver disease/cirrhosis) combined.

Despite the high burden of cancer present in both of these populations, their inclusion as community partners on the OUCNP is significant in that striking dissimilarities in collaborative capabilities exist among these specific African American and tribal community partners. Generally, the most glaring differences in collaborative capabilities are infrastructural and economic disparities that exist among these communities. Both tribal nations, for example, are at the forefront of the most prosperous areas of growth in the state, including being in the top 20 employers for the entire state of Oklahoma. Many of the All-Black towns, in contrast, represent some of the most economically and socially depressed areas in the state.

Such contrasts urge us to consider how highly disparate communities begin the difficult work of creating effective, equitable collaborative research partnerships, particularly as notions of 'equal' and 'collaborative' appear increasingly out of reach for some communities. At the core of the OUCNP is a commitment to community-based participatory research (CBPR) as both an approach to research design and a method for achieving measurable outcomes. CBPR promotes the idea that collaborative partnerships enable more equitable opportunities for community engagement, as well as more prominent roles for community partners in the ownership and control of project outcomes. This article explores the implications of conducting CBPR projects with inequitable community partners,



and how such partnerships are only truly collaborative once the infrastructural disparities that emerge within and among community partners are addressed.

CBPR, THE OUCNP, AND COMMUNITY DISPARITIES

Community-based participatory research (CBPR) emerged as a constructivist-inspired and critical theoretical alternative to positivist paradigms in research (Israel et al. 1998; Wallerstein and Duran 2003). CBPR approaches focus on the mobilization of marginalized or vulnerable communities, “whose members experience limited access to resources and decision-making processes” (Israel et al. 1998:194). A central principle of CBPR is the importance of facilitating “collaborative, equitable partnership in all phases of the research, involving an empowering and power-sharing process that attends to social inequalities” (Israel et al. 2003: 56). The participatory legacy of CBPR crosses disciplines and has roots in a number of similar approaches that hold as their centerpiece three inter-related elements: participation, research, and action (Minkler 2005; see also Minkler 2004). These foundations challenge long-held standards within academia, including unequal power relations between researcher and subject, institutional guidelines for determining what is appropriate and effective research, and even funding trends in the public and private sectors (Minkler 2004: 687).

Inherent in statements about CBPR is the idea that partnership in community research always means *equal* partnerships. As described below, however, the collaborative capabilities of the community partners on the OUCNP are strikingly different, particularly with regard to financial resources and infrastructural capacity. Power imbalances among community partners resulting from differences in financial and infrastructural capacity can lead to “participation without influence,” or the invitation for communities to participate in some aspects of research but to not have influence over other parts (Schulz et al. 2002: 291). The following questions should therefore accompany evaluations of the use of CBPR in disparate communities. How do CBPR approaches currently account for differences in partnership capabilities? Is CBPR prepared to revise conventional classifications of *vulnerable* populations, particularly as these communities (as is the case with some tribal nations) procure more genuine self-representation as a result of self-contained institutional review boards, economic sustainability that overwhelms most university subcontracts, and infrastructures that are competitive at the state and federal levels? Should funding agencies and research institutions apply singular standards of evaluation to collaborative projects, such as the OUCNP, that incorporate highly disparate communities as research partners? Should all partners’ obligations and

responsibilities to a project be the same? If not, what are the implications for CBPR projects that seek to reduce health disparities but do not challenge infrastructural disparities among partners? In short, is CBPR either *collaborative* or *equitable* if it addresses one form of disparity while turning a blind eye to another? Answering these questions and drawing distinctions among collaboration, participation and equity in research are important as researchers and community members seek to affect health disparities outcomes in historically and culturally distinct communities.

CBPR has great potential to impact health disparities in communities “where there are social injustices and...to make changes in policy and the environment rather than changes in individual behavior” (Malone et al. 2006: 1915). The University of Oklahoma Community Networks Program (OUCNP) consists of a network that includes a consortium of academic researchers, health professionals and advocates, and three community partners: two tribal nations in Eastern Oklahoma, and an organization representing the Historic All-Black towns of Oklahoma. Activities central to the OUCNP include the improvement of cancer screening services, development of partnerships, pilot research projects, training of local health navigators, securing of external funding, and the implementation of community-specific activities geared toward increasing cancer screenings. The OUCNP consists of three phases designed to meet the study’s overall goals: capacity building, community-based research initiatives, and sustainability.

DIFFERENCES IN INFRASTRUCTURAL CAPACITY

Independent efforts by each community partner to fulfill these three phases reveal the infrastructural disparities that existed among the community partners over the duration of OUCNP efforts. The two tribal partners began work on the final phase (sustainability) as partners working in the All-Black towns, as described later in this article, found it difficult to come by successes in the first phase (capacity building). The tribal partners largely employ their own tribally operated health care services while the All-Black towns rely heavily on partnerships with existing state services and health advocacy groups. The two tribal nations each have their own tribal health facilities, including multiple clinics and even hospitals in their tribal jurisdictional service areas (TJSA). One tribal partner operates ten separate health facilities in their tribal jurisdictional area, and the other operates eight such facilities. Each tribe has its own hospital and cancer programs for use by its citizens. Meanwhile, the All-Black towns have few such services and rely heavily on the OUCNP itself to arrange free or low-cost cancer screening services for town residents.





I will compare the capacities of one of the tribal partners and one of the All-Black towns to demonstrate further the differences in infrastructural capacity. The tribal nation is one of the largest in Oklahoma and at the forefront of tribal and state efforts to provide first-rate healthcare to its citizens. Preliminary organizational assessments for this tribal nation indicate at least twenty-four distinct agencies, both internal and external to the formal tribal organization, whose services directly impact the management of risk factors known to affect a population's health. In addition to involvement with tribal cancer programs, tribal programs offer services including financial and housing assistance, environmental protection, career services, food distribution services, veteran's assistance, mental health services and others. These programs address physical, psychological, financial and social needs, thus complementing the broader goals of tribal health services to create a healthy community environment for tribal citizens. While these agencies may not all participate directly in the effort to reduce cancer in the tribal population, each is valuable to the public health infrastructure of the tribe.

An organizational assessment of one of the rural All-Black towns reveals strikingly fewer agencies that provide health-related services specifically for town residents. This town has no established clinics in operation, and there are no services devoted to the facilitation of healthier residents. Many of the health screening agencies currently operating in this town participate as a result of partnerships established through OUCNP researchers and other outreach workers. Indeed, the only health-related infrastructural components in this town independent of OUCNP are a community improvement grant for nutritional programs, monthly dentistry services, and a local health clinic that operates irregularly and without steady personnel. Conducting cancer awareness activities, much less actual screenings, in towns like this with a blatant lack of established resources is difficult.

The dissimilarities in infrastructure between the tribal partner and the All-Black town described above are clear. This comparison tells us a few things: the screening implementation process that works for one set of partners is not necessarily going to work for another, the lack of sustainable resources in some communities suggests a need for innovative interventions at the local level, and we should not limit ourselves to the enhancement of *existing* infrastructure but should also promote the development of *new* infrastructure. Finally, the disparities above speak to the need for a better understanding of the local conditions that affect project outcomes and that create major differences among the participating communities in the OUCNP. Such local assessments can also help point out limitations inherent in the CBPR paradigm.

HEALTH, CANCER, AND COLLABORATIVE RESEARCH IN AN ALL-BLACK TOWN

The All-Black town featured in the above comparison is one of the largest of the historic All-Black towns located in eastern Oklahoma. "All-Black Towns," a formal designation referring to a specific number of historic towns, were established largely throughout eastern Oklahoma between the end of the Civil War and the early 1900s as utopian enclaves (McAuley 1998). These historic communities, many established prior to the formation of Oklahoma statehood in 1907, were founded upon the journeys of black migrants from the Deep South who sought the promise that an All-Black Town held in the early 1900s. Residents in the towns were recruited primarily from the southern United States. A promotional ad recruiting residents for a growing All-Black town in 1905 reads, "This is the homeseekers [sic] opportunity to secure a good home in a Negro town.... Join the number and spend one week in a Colored town where everything is owned and controlled by Colored people." The Great Depression, however, dried up the flow of migrants into the towns as it dried up the towns' once booming economies. Over the last 50 years, these towns have experienced more out-migration than in-migration. The original 30 All-Black towns have now been reduced to 12, ranging in population from 34 to 1,441. The town at the focus of this article remains one of the largest All-Black towns with an official population of 1,126. This number includes a substantial Mennonite community and the population housed at the local correctional facility, both located in the town's limits but notably outside of the local community structure.

The promise of greater opportunity in distant places has caused this town's population to be older than the general population of Oklahoma, composed mainly of descendants of the original town founders, not new residents. By nearly all accounts, including those of residents, the heyday of this particular All-Black town is long passed. A newspaper description of the town in 2005, one hundred years after the town recruitment ad, reads, "The overriding spirit of the town had been self-sufficiency outside the white power structure. But today, that fight is about over, at least in the West, and [it] is on the verge of blowing away on the wind" (Jonsson 2005). The once flourishing downtown area of this All-Black town, according to *Preservation Oklahoma*, now "lacks the economic reinvestment needed for it to flourish" (preserveok.org). In fact, many of the All-Black towns in this project represent some of the most economically depressed communities in the state.

Today, the buildings in the town's historic business district remain largely vacant and absent of consistent economic activity. The residential lots surrounding the immedi-





ate downtown area are often overgrown, and the town's only public high school was recently shut down due to lack of resources and enrollment. Pecan Street, the town's main street, is peppered with cars that seemingly go nowhere from day to day. These cars are points of convergence for mostly male residents without reliable employment, as well as points of contention for town elders who believe these young men could be more productive. Pecan Street is where local news travels, where social relations are fostered, and where town residents keep track of visitors entering town.

The town at the center of this article, while listed on the Preservation Oklahoma's Endangered Places list ("Places to Watch" n.d.), strives to maintain the remnants of the once-flourishing downtown commercial district that is now listed in the National Register of Historic Places (NR 75001568). Despite social and economic challenges resulting from changing demographic trends and low economic productivity over the past several decades (Boddie 2002: 324), the town's present-day vibrancy continues to be grounded in the families that founded the town and who are still represented at local family reunions, the annual rodeo, memorial services, and holiday celebrations. A local community-based revitalization organization has recently made great strides to improve the community, particularly in the areas of agriculture, economic development, education, fundraising, government, public relations, tourism, and cultural revitalization ("The Town of Boley" n.d.). The town has been successful in acquiring community improvement grants, most recently including the *Reader's Digest We Hear You America*, a national campaign to recognize grassroots efforts of towns facing economic hardship during the recent recession (Reader's Digest 2011). The foundation for many community rejuvenation efforts remains the families and community institutions that have grown this town since its inception in the early 1900s. The town's many active church congregations and congregants, more than county or statewide organizations, remain one of the most constant sources of both informal and formal social service programs for community residents (Boddie 2002: 325).

I have worked in this particular All-Black town on and off for about six years on various cancer-related projects. I began work on the OUCNP nearly two years after the project's inception, and it was under the auspices of "collaborative research" that I again came to travel north on the familiar Pecan Street to work with town residents. Residents almost always prove willing to at least hear about the "next cancer project," though it is unclear how much they really expect it to help. Periodic cancer awareness events indicate that residents are interested, and perhaps hopeful, that resources are increasingly available to

them. Town elders fervently collect bags of awareness materials for themselves and others who do not make it out to local cancer functions but might appreciate the gesture. On the other hand, town residents do not generally take advantage of free cancer screenings offered through coupon, appointment, or "group screening" day, when accommodations are made to transport residents into the city for a free mammogram or colonoscopy. I spoke about these frustrations to the one-time nurse who would drive three hours a day to give her time in a rundown clinic on Pecan Street. She reiterated what I knew from years before: you offer free services long enough and consistently enough and you might just get residents to *think* about it. Awareness is good if you want to start to see results in these towns—but trust is better.

TRUST AND THE RESEARCH RELATIONSHIP

Mistrust of researchers within many African American communities is central to many residents' perceptions of the illness experience and their health-seeking behaviors. The lack of trust that accompanies many research endeavors, particularly in underserved populations, has been well documented (Chataway 1997; O'Fallon and Deary 2002; Wallerstein and Duran 2003). According to Israel et al. (1998:183), mistrust in community-based research is "based on a series of research endeavors that produced no direct benefit (and possibly harm) to the participants, no feedback or dissemination of research results back to the community, and a lack of sustained effort on the part of researchers to maintain relationships." Some studies indicate that African Americans are less willing to participate in research studies and clinical trials (Shavers-Hornaday et al. 1997). Residents in the All-Black towns frequently cite the Tuskegee Syphilis trials as evidence of the mistreatment of African Americans by the biomedical community, and data from these communities suggest that residents minimize both "their dependence on interactions with outsiders" and the "use of extra-community health resources" (Foster 2004:509). Specific practices include downplaying signs of illness, delaying biomedical treatment, and bypassing treatment facilities in predominantly Euro-American communities in favor of more distant, urban facilities perceived to be more accepting of minority patients (Foster 2004). These practices, combined with the absence of local health care resources, contribute to high mortality rates from cancer and negative health experiences for community members.

One of the few public places in this All-Black town, aside from local churches, to regularly engage residents is the Community Center located on Pecan Street. A senior lunch program provides elder residents with a warm meal and an opportunity to socialize and, of course, an occasion



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for researchers to be present. The senior lunch in this town is highly illuminating of dynamics in the community associated with gender, age, race, and even subtle distinctions based on one's status as a community insider. A group of four Caucasian men in their thirties and forties came into the community center for lunch one day. The men's uniforms made it clear that they were some type of construction workers, and the boldness with which they entered the room and sat at the first available table made it clear that they were outsiders to the community. The men unknowingly sat at the "women's table," yet another indication that they were unaccustomed to local conventions. Despite my interest in watching this uncomfortable dynamic play out, I let the men know that they (not to mention the women) might be more comfortable if they moved to the other table. The men moved, only to have an elder man make it clear that the lunch was not intended for them anyway, to which the visiting men abruptly left. I understood the men's discomfort, as I had eaten lunch there while sitting across the table from the same woman for two years before she ever initiated conversation with me. Wariness of outsiders, not unlike many inclusive rural communities throughout Oklahoma, is expected in this town.

To build trust in a town like the one described in this article one must be *persistent*; to maintain it one must be *consistent*. The same nurse who once gave this advise to me eventually discontinued her own work at the local clinic on Pecan Street amid rumors of administrative wrongdoings. Residents in the town seemed uninterested in probing the details of this incident, presumably because they have become accustomed to sporadic cases of resource mismanagement and business venture failings. My frustration at the clinic's closing appeared greater than the frustrations of residents who stood to gain the most from the clinic and any cancer screening programs that might be housed in the clinic. This clinic had been the most promising location for one such local cancer-screening program known as Take Charge!, an Oklahoma State Department of Health program that offers free mammograms and clinical breast exams to underserved women across the state. The program currently has regional nurses operating in every county in eastern Oklahoma except for Okfuskee County, where this particular town is located. The implementation of this program in this community would have been the first such cancer screening service to directly impact residents of an All-Black town. Plans to implement the program in the run-down clinic involved a collaboration of state health institutions, regional nurses with the Take Charge! Program, OUCNP outreach coordinators, the former clinical nurse, and interested community members. OUCNP staff also had begun to train local residents to serve as community health

navigators, a role that would enable locals to recruit participants, schedule appointments, and provide patient follow-up.

The implementation of a Take Charge! Program in this community was underway for the last two years of the OUCNP, and town residents expressed enthusiasm at the prospect of being able to access and oversee local breast cancer screening services. Every step forward in the building of this local initiative, however, seemed to be followed by at least two steps back. Plans to open the new Take Charge! clinic were abruptly suspended at the request of the State program directors. A number of circumstances, some mentioned in this article and others still unknown, led to the suspension of plans for this Take Charge! clinic. The successes and, more often, the challenges of such efforts bring pause to the idea that collaborative research is a concrete means to systematically rewrite the everyday realities that shape the health of a community. The steps taken by the OUCNP, however, reinforce the ongoing need to develop sustainable resources and platforms on which mostly rural towns like Oklahoma's All-Black towns can participate more fully in collaborative efforts to reduce cancer disparities.

Efforts to promote free cancer screenings to town residents have thus far been ineffective, in part, because the screenings are conducted in largely Euro-American areas or urban areas at least an hour away from the town. Despite arrangements for qualified residents to receive free breast, cervical, colorectal and prostate screenings in neighboring cities, the only screening activities that have attracted participants from this particular town have been Prostate Specific Antigen (PSA) blood tests conducted on-site. The Oklahoma Blood Institute (OBI) performs PSA tests for a fee of \$85 (or \$65 if also donating blood). OUCNP researchers secured funding from the Oklahoma State Department of Health for payment for these tests. On-site screenings are concrete interventions that directly address transportation barriers and time limitations. Perhaps more importantly, on-site screening programs potentially create locally monitored environments that enable town residents to develop trust in state agencies willing and eager to provide services in an otherwise overlooked area of the state. To be clear, successful effort to implement the Take Charge! Program in this town would have absolutely satisfied the need for a locally monitored cancer screening service had such plans not been abandoned with the closing of the local clinic.

It is not a coincidence that towns like the one described in this article have been excluded from many public health initiatives. The following are reasons given to me by various health providers for not performing on-site





screenings in Oklahoma's All-Black towns: low turnout rates, apathy, noncompliance, or suggestions that outreach workers might be more comfortable (or even safe) in more 'neutral' location outside of the towns. As a Caucasian female advocating for health screenings in the All-Black towns, other Caucasian health service providers have expressed to me on multiple occasions their own fears, hesitations, and even aversions to working in the areas surrounding these towns. It is critical to make public health institutions and health providers aware of the specific and accurate barriers that exist in underserved communities, and to provide suggestions for overcoming them. The most effective way OUCNP could address issues of mistrust, and to affect health seeking behaviors resulting from that mistrust, is to implement a local cancer screening program to create a platform on which community partners can serve their towns, residents, neighbors, and concerning the OUCNP, to participate as influential partners in collaborative research goals.

CONCLUSIONS AND LESSONS LEARNED

The case in this article suggests that CBPR projects must not invite participation from disparate community partners without addressing health disparities in community-specific (and relevant) ways. This observation speaks to the important distinction between "participation" and "participation without influence." Misguided or unmediated inclusion of inequitable community partners in research can lead to further marginalization of one group. Further, highly disparate community partners stand to experience increased frustration at differences in measurable achievements among groups. Inattention to dynamics among disparate community partners has the potential to disenfranchise current or future community partners in CBPR initiatives.

The challenge for collaborative research, according to Krieger and colleagues, is "to equalize the power imbalances between less influential community partners and more powerful public health researchers" (Krieger et al. 2002: 374). I do not fully buy the idea that collaborative research alone is ever capable of equalizing the power imbalances that exist in some of the communities in which we work; an "equal but different" approach only denies the material and experiential consequences of inequality (see McDowell and Jeris 2004: 82). "Community partners" and "equal partners" are not synonymous; the comparative examples of the tribal partner and the All-Black town make this clear.

The results of the OUCNP also suggest the value of capacity building to the success of all phases in multi-partner, collaborative projects. The OUCNP produced a number of great successes over the past five years, par-

ticularly the marked increase of reported cancer screenings among tribal partners. During the first two years as a partner on the OUCNP, one tribal partner reported marked increases in tobacco, breast, and colorectal screenings, decreases in obesity rates, and increases in rates of physical activity, tobacco cessation, and participation in tribal healthy living activities. The tribe's health services reported colorectal cancer screening rates among adults aged 50 and over increased from about 30% to nearly 38% between 2006 and 2007. These rates continued to increase from about 45% to over the *Healthy People 2010* goal of 50% between 2008 and 2009 (Grim 2010). In contrast, OUCNP's efforts to impact cancer screening rates in the All-Black towns were less effective as a result of infrastructural barriers and local concerns discussed in this article. For example, only a single resident from one of the partnering All-Black towns participated in a free colorectal cancer-screening program over the duration of the OUCNP. Perhaps more measurable outcomes in cancer screening would have been possible for all OUCNP community partners if infrastructural disparities among them had been less pronounced and if project goals had been more relevant to the needs of each partner. The OUCNP ended in 2010 and applications for grant renewal were submitted shortly thereafter. The All-Black towns were not included as independent community partners on the grant renewal, a decision that represents the compromises researchers sometimes make to engage in CBPR. The OUCNP did not receive funds for renewal.

A cornerstone of CBPR is more prominent roles for community partners in the ownership and control of project outcomes. Despite the discrepancy in measurable outcomes among OUCNP community partners, such as increased cancer screening rates, it is important to note that residents in the All-Black towns did not compromise locally established and preferred health-seeking practices to compete more equally with the tribal community partners. Town residents maintained control over their own levels of participation in project activities, with some town residents choosing to pursue cancer screening and follow-up care independent of OUCNP initiatives. Residents in the towns exhibited a general reluctance to participate in OUCNP cancer screening activities, particularly when these services required residents to travel outside of their communities, depend on outsiders, or participate in non-local or state-sponsored programs. The outcome, therefore, is not to have equal impacts among disparate communities but to establish localized resources to serve and respect disparate needs.

Revisiting a question posed earlier in this article: is CBPR prepared to revise conventional classifications of vulnerable populations without also addressing the possi-



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bility that inequitable outcomes in community-based interventions are both realistic and meaningful? Krieger et al. (2002: 374) suggest, "partners in community-based research determine the degree and nature of participation that is best suited to the project at hand." Collaborative participation is ineffectual if even one community partner participates in research without the same capability to exercise influence over the research. Success in CBPR projects must not be exclusively measured by increased resources, decreased cancer incidences, or the ability to secure funding. Success should instead rest on the establishment of goals relevant to local needs and attainable according to the existing and potential capacities of all research partners.

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