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Community-based participatory research (CBPR): A new and not-so-new approach to HIV/AIDS prevention, care, and treatment

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After nearly 30 years since the identification of HIV, a vaccine or effective cure still eludes us. Furthermore, our current challenges in providing access, and ensuring uptake and consistent adherence, to antiretroviral (ARV) medications indicate that the epidemic will continue to challenge educators and practitioners, clinicians and providers, and advocates and policy makers, even after a viable vaccine exists (Rhodes, Hergenrather, Wilkin, & Wooldredge, 2009). Currently, the most effective means to confront the HIV epidemic are to reduce (a) behavioral risk, (b) seropositive infectivity, and/or (c) biological vulnerability to infection. However, clearly our current arsenal of effective approaches to increase adherence to risk reduction strategies and treatment remains insufficient. This Theme Issue of *AIDS Education and Prevention: An Interdisciplinary Journal* explores how community members, organizational representatives, and academic researchers can combine their knowledge, perspectives, experiences, and resources to systematically inform and promote HIV prevention, care, and treatment in meaningful and effective ways through community-based participatory research (CBPR).

We know that understanding and intervening upon complex health problems such as HIV/AIDS benefit from the multiple perspectives of community members, organizational representatives, and academic researchers (Agency for Healthcare Research and Quality, 2002; Centers for Disease Control and Prevention & Agency for Toxic Substances and Disease Registry Committee on Community Engagement, 1997; Green, 2001; Hergenrather & Rhodes, 2008; Institute of Medicine, 2000; Israel, Schulz, Parker, & Becker, 1998; Viswanathan, et al., 2004). Research aimed at understanding and promoting health has increasingly focused attention on CBPR (Eng, et al., 2005; Institute of Medicine, 2003; Israel, et al., 1998; Rhodes, et al., 2006; Viswanathan, et al., 2004; Wallerstein & Duran, 2003), recognizing that a community “outsider,” such as an academic researcher, can work best with community partners, who themselves are experts (Rhodes, et al., 2006; Rhodes, Hergenrather, Ramsey, Yee, & Wilkin, 2007). Blending lived experiences with sound science has the potential to develop deeper understandings of phenomena, and thus, produce more relevant and more likely successful and impactful interventions.

Community-based Participatory Research Defined

CBPR is an approach that ensures community participation in research. CBPR establishes structures for full and equal participation in research by community members (including those affected by the issue being studied), organizational representatives, and academic

researchers to improve community health and wellbeing through multilevel action, including individual, group, community, policy, and social change. CBPR emphasizes co-learning, reciprocal transfer of expertise, and sharing of decision-making power among community members, organizational representatives, and academic researchers. It also emphasizes the mutual ownership of the products of research (Cashman, et al., 2008; Viswanathan, et al., 2004). Research belongs not only to academic researchers, but also to community members and organizational representatives.

Community members, organizational representatives, and academic researchers also participate in and share control over all phases of the research process, e.g., assessment; problem definition; methodology selection; data collection, analysis, and interpretation; dissemination of findings; and application of the results (action). A distinctive feature of CBPR is that research should move towards action through translation of findings into their application in the community (Arcury, Austin, Quandt, & Saavedra, 1999; Cornwall & Jewkes, 1995; Israel, Eng, Schulz, & Parker, 2005; Minkler, 2005; Rhodes, Eng, et al., 2007; Rhodes, et al., 2006; Rhodes, Hergenrather, Yee, et al., 2007; Solomon, Card, & Malow, 2006; Viswanathan, et al., 2004). Such action may include further research to understand phenomena to intervene more effectively; or intervention development, implementation, and/or evaluation. Action also may include policy advocacy and changes in practice or policies.

CBPR is inherently translational. CBPR ensures that formative research is conducted with an eye on its potential and practical use, or next steps to move towards its application to improve community health. Research may begin with an assessment of needs, based in community perceptions and epidemiologic data, and then progress to the community change. Similarly, community-level knowledge can inform the formative process, guiding how resources (including effort, money, talent, etc.) are focused.

This Theme Issue includes descriptions of five diverse studies that outline the processes of and outcomes associated with rigorous CBPR. We have identified key characteristics and components of CBPR as they emerge from and are applied in HIV prevention, care, and treatment. These characteristics and components also are presented in Table 1 and elaborated below.

Community-based Participatory Research Applied

First, by its definition, CBPR requires a partnership comprised of community members, organizational representatives, and academic researchers. A partnership is the foundation of CBPR and depending on past experiences of working together, establishing a partnership may vary in difficulty. Building and nurturing a CBPR partnership requires a commitment of time and effort of all partners. CBPR does not occur within a vacuum, but is a dynamic process that involves a long-term commitment (Israel, et al., 2003). For example, partnerships are rarely research study specific. More often, they constitute ongoing commitments of all members that are paramount to one particular CBPR study or project. Members may join and leave, or be more or less involved, but despite transition, the partnership remains. Moreover, partnerships may have several CBPR studies going on simultaneously. These efforts may include a variety of studies to meet the needs of various priorities, and/or subgroup or subpopulation needs, and these efforts may be at different stages of development. For example, our CBPR partnership in North Carolina has projects to (a) explore sexual risk behavior and potential intervention strategies among Latino men who have sex with men (MSM), (b) test an intervention study to increase condom use among male heterosexual Latino soccer team members, (c) develop a lay health advisor (LHA) intervention to prevent HIV risk among Latinas, (d) replicate and evaluate a comprehensive

risk counseling services (CRCS) intervention for persons living with HIV/AIDS (PLWHA), and (e) implement and evaluate an online chat room-based intervention to promote HIV testing in chat rooms. The key is that CBPR requires an ongoing partnership that is not merely tied to a single study or funding source; in fact, partnership members are committed to, and involved in, the partnership – with or without funding.

However, it also is important to note that CBPR is more than the inclusion of partners. CBPR begins with an identification and exploration of community needs, priorities, and assets. As Rudolph et al. describe in this Issue, the established Harlem Community and Academic Partnership (HCAP) explored published and unpublished research including epidemiologic data, conducted community focus groups to examine perspectives, and held iterative discussions with community leaders and organizational representatives to help determine community health priorities. The process led to identifying substance abuse and infectious diseases as top priorities on which to intervene. The authors credit much of the success of the development, implementation, and impact of the intervention, both on the initial participation of providers at pharmacies and among injecting-drug users (IDUs), to this first step of identifying community needs and priorities. Prioritization of needs and potentially effective approaches was based on mutual negotiation among community members (e.g., IDUs), organizational representatives (e.g., pharmacy staff, HIV testing centers, and drug detoxification centers), and academic researchers from Columbia University.

The importance of linking community needs and priorities with academic researcher interests and skills cannot be overstated. Just as community priorities must be respected, academic researchers must be honest with communities about where their interests and skills overlap and complement. Academic researchers should not prioritize community priorities without regard to the epidemiologic data; in fact, community members and organizational representatives may rely on academic researchers to provide that epidemiologic data and thereby provide a context for their perspectives. Thus, education and negotiation among community members, organizational representatives, and academic researchers are warranted to establish priorities. Through iterative negotiation, these priorities are more informed. In the case of HIV/AIDS, communities that are most impacted by the epidemic may have: (a) surrendered the fight because of competing needs and priorities, (b) assumed HIV is “someone else’s problem,” (c) thought that all that is possible is being done, or (d) lack awareness that HIV remains a health threat and has transitioned into a chronic disease requiring ongoing support structures to maintain healthy behavior. In the southeastern US, a region of the country disproportionately affected by the epidemic compared to other regions of the US (Centers for Disease Control and Prevention, 2008; Lieb, et al., 2009; Rhodes, Hergenrath, Wilkin, & Jolly, 2008), we have observed communities that continue to respond to the epidemic as if HIV remains predominantly a gay disease or most related to bisexual behaviors.

Communities may choose to focus on other health issues (e.g., diabetes, cardiovascular disease, etc), and academic researchers who hope to partner with these communities may have to confront difficult choices. Without negotiation of priorities, it is unlikely that anyone will be effectively served or community health enhanced. In an effective CBPR partnership, all members should have access to information, including epidemiologic data, and various perspectives to understand its meaning. As a CBPR partnership is developed, nurtured, and maintained, academic researchers should listen to community members and organizational representatives and also contribute their insights.

Another hallmark of CBPR is the multidirectional exchange of information and learning. All partners – community members, organizational representatives, and academic researchers –

work together and share experiences and perspectives to develop a deeper and more informed understanding of phenomena. The goal is to generate realistic intervention and authentic study designs that can be well implemented, with high ecological validity. For example, as detailed in this issue, Griffith et al. developed a multilevel intervention for faith-based institutions designed to engage church youth, adults, pastors, and pastor spouses. In this study, the academic researcher brought to the group theory-based understanding of behavior, access to what has been tried in other communities, and what has been identified as successful and unsuccessful in terms of intervention and risk reduction. Community members brought their lived experiences and insights that only “insiders” will know and understand. These experiences and insights included further networking and needed partnership expansion, and how this could occur (i.e., including clergy spouses in the process); what approaches are likely to be acceptable and meaningful within the community context of the congregation (e.g., how to frame HIV prevention within congregations); and how evaluation could be realistically accomplished. Organizational representatives brought generalizable experiences from the field. This multidirectional exchange requires a high level of openness and trust among partners that demands time and effort to build.

A fourth key characteristic of CBPR includes openness and trust among CBPR partnership members, which require the members to think critically, not only of how perspectives blend to yield meaningful knowledge, but also about power (Chavez, Duran, Baker, Avila, & Wallerstein, 2003). Often in funded research, the academic researcher may have the qualifications and reputation to apply for funding. Because of this inherent power imbalance, the meanings community members and organizational representatives give to perspectives and assertions may deviate from the academic researcher’s intentions. The academic researcher may be viewed as holding the “purse-strings.” Furthermore, partnership is typically enhanced if representatives from state and local public organizations (e.g., health departments) remain aware of the power they may have, or the power that community members may perceive them to have, as they allocate resources, make funding decisions, and design projects. If a true commitment to CBPR exists, partnership members may benefit from being aware of how they may be perceived by other members in terms of power and resources and examining and evaluating their own commitments to power sharing. Open communication and transparent processes support openness for mutual understanding of perspectives.

Trust also takes time to build, which varies depending on a community’s history of challenging relationships with institutions and academic researchers. The building and maintenance of trust is a pre-condition of effective CBPR. Although community trust (or more often distrust) in research and the academic researcher is discussed in the literature (Becker, Israel, & Allen, 2005; Corbie-Smith, et al., 2003; Eng, et al., 2005; Rhodes & Hergenrather, 2002; Viswanathan, et al., 2004), trust by researchers in the process has not been well explored in the literature and deserves further exploration (Rhodes, Eng, et al., 2007).

Power sharing is another key element of CBPR. To effectively achieve this, however, an effective CBPR partnership requires established ways for community members and organizational representatives to access resources and share in decision making. In this Issue, Corbie-Smith et al. describe how an emerging partnership applied an established staged approach to partnership development (Florin, Mitchell, & Stevenson, 1993). It included establishing an organizational structure to help ensure shared decision making.

Power sharing may be challenging for academic researchers. First of all, it may seem antithetical, given the typical academic training to reduce threats to validity and increase generalizability. However, power sharing helps to ensure that all those with a stake in the

research are included and have a mechanism to have their voices heard and respected. Furthermore, tradeoffs often must be made in research, and it is imperative that CBPR partners are fully informed of the various outcomes that different decisions may yield.

It is important to ensure that community members, organizational representatives, and academic researchers realize potential outcomes of various decisions that the partnership makes. These outcomes may include how studies may be perceived by grant reviewers (and thus affect funding) and the ability of study designs to produce the knowledge and evidence that partners may want. Similarly, effective partnerships typically involve sharing insights into what realistically can be done within a study, which serves to further inform research-related decisionmaking. Power sharing also tends to imply sharing financial resources. The papers in this Issue do not describe resource allocation; however, as one proxy of power sharing, in our CBPR studies, our partnership has allocated 40–50% of the direct federally funded cost of HIV-related research projects to organizations within our CBPR partnership.

Besides power sharing, CBPR ensures that the products of research are shared by partnership members. For example, all papers in this Issue are co-authored by community members, organizational representatives, and academic researchers. Thus, the successes and the challenges of research are shared. This sharing of the products of research also enhances dissemination of findings because of the synergy of the networks contributed by each partner. Research does not only get published in academic journals but may be disseminated in practitioner outlets and meetings at the local level.

A seventh key feature of CBPR is related to its potential to increase individual and community capacity. By working in partnership, individual and community-level capacities are developed. These capacities may include an increased understanding of how to affect change among individuals and within communities, and the development of community mobilization, problem-solving, and even public speaking skills. Outcomes such as these that are associated with using CBPR may be vital in reducing the impact of HIV because they build the capacity for communities to act on their own behalf (Gupta, Parkhurst, Ogden, Aggleton, & Mahal, 2008; Vissman, et al., 2009). Such skills are transferable to confront the evolving needs of the epidemic as well as other needs of vulnerable communities disproportionately affected by HIV. Given the “syndemic” manner in which HIV tends to cluster around other problems like poverty and other stigmatizing, disempowering, and marginalizing conditions that contribute to health disparities (Singer, 1994; Stall, et al., 2003), building individual and community capacity may be an effective approach to reducing and eliminating health disparities.

Related to building capacity, CBPR supports sustainability, dissemination, and/or the development of next steps. Some projects may not warrant sustainability (e.g. projects that do not produce desired results, etc.); however, some successful or promising projects may be sustained by the community. For example, after a study has been found effective, a community organization may choose to further develop the project, replicate the project, or adopt it as a program within their scope of work. Similarly, CBPR may yield subsequent efforts. Through their involvement in the in a CBPR study, partners may identify other needs, and they may have developed the skills, and perhaps trust as a partnership, to creatively meet those needs.

Finally, it is important to emphasize the “R” in CBPR; CBPR is research. To lay a firm foundation on which to do research, building research capacity may be required. Partnerships are most effective if based on mutual understanding of one another’s perspectives. Human subject protection; study designs and their strengths and weaknesses; ways in which knowledge is accumulated and how different ways of knowing are assessed

and evaluated; and how studies contribute to one another, build understanding and evidence, and can be used in the field to inform and improve practice and the health of community members all should be explored within CBPR partnerships and understood by partnership members. Although there often is tension between “participation” and “research,” it is helpful for all partners to be explicit about their assumptions and remain cognizant that CBPR is an approach to research.

Partnerships that hope to gain federal research funding for CBPR must gain credibility in much the same way that all research teams do: beginning small (e.g., smaller scale studies to collect formative, feasibility, and pilot data); disseminating findings from these preliminary studies in peer-reviewed journals that are perceived as impactful; and building and providing evidence that the partnership adheres to CBPR principles. Furthermore, findings from CBPR may, in fact, be more valid than other approaches given that multiple perspectives come together to determine priorities, the study design, and data collection and methodologies. These findings may have just as much (or more) relevance in other settings as findings discovered using more traditional approaches to research; after all, we know that communities of IDUs, African American congregations, MSM, CSWs, and immigrant Latinos, as examples, differ widely. What is learned within one study needs to be interpreted within the context of that setting, whether CBPR was used or not.

Challenges for the Future

Despite the promise of, and the expanding emphasis on, CBPR, few studies have combined authentic community-academic partnership with solid research and evaluation methods. Two common challenges identified in the current and growing body of CBPR literature are that (1) much time is devoted to partnership development rather than to the research study, and (2) little attention is given to whether an intervention affects health outcomes. Often the effects of CBPR studies are obscured by reduced rigor (Cashman, et al., 2008; Viswanathan, et al., 2004). However, this Theme Issue was designed to move CBPR – at least in HIV prevention, care, and treatment – forward. Clearly, partnerships vary regarding their level of adherence to standards of CBPR in terms of process (Hergenrath & Rhodes, 2008; Horowitz, Robinson, & Seifer, 2009; Minkler, et al.; Reece & Dodge, 2004; Rhodes & Benfield, 2006; Rhodes, Eng, et al., 2007; Vissman, et al., 2009; Viswanathan, et al., 2004). However, there continues to be debate over three key questions: Does CBPR improve (1) research quality; (2) understanding of phenomena; and (3) health outcomes?

Although the blending of perspectives of community members, organizational members, and academic researchers appears reasonable, the evidence remains limited. The authors of the papers included in this Theme Issue recognize that although CBPR is promoted within the literature and in funding announcements, further and more refined research is needed. Moving from partnership building and maintenance to impacting community health requires a next level of research. We must build on successful partnerships (e.g., partnerships that are well established, have a track record of “doing” CBPR, and have reliable mechanisms for full and equal participation of all members in decision making) to explore the impact these partnerships and their approaches can have on the health of communities. Moreover, investigation is needed of the key characteristics – and their operationalization – and the mechanisms of CBPR that contribute to its success; and how different types of communities “interpret” CBPR.

As has been noted, there is no single way of “doing” CBPR. What works within one community may or may not work equally well within another; however, there are guiding principles that serve as an initial framework for CBPR partnerships. These guiding principles have been elaborated elsewhere (Israel, et al., 1998; Israel, et al., 2003) and

include: (1) recognizing the community as a unit of identity and strengthening community through collective engagement; (2) building on strengths and resources within communities; (3) facilitating partnership member power sharing within all phases of research; (4) promoting multidirectional learning and capacity building among partners; (5) focusing on action-oriented research for community health improvement, the reduction and elimination of health disparities, and the mutual benefit of all partners; (6) emphasizing community priorities, ecological perspectives, and the multiple determinants of health; (7) developing competencies to work together and engage thoughtfully in community-based research; (8) disseminating findings to all partners and engaging all partners in the dissemination process; and (9) committing to long-term partnership that is firmly founded and not tied to one study. Thus, the papers within this Issue offer no rigid recipes for CBPR. Rather, they offer examples of how these principles were used, adapted, and/or expanded.

There also remains a pressing need to move towards outcomes, while fully measuring process factors that are linked to outcomes. After all, key to CBPR is research and a hallmark of the approach is movement towards action. The collection of papers in this Issue is designed to move the science of CBPR forward in this direction with authors linking processes to proximal and distal outcomes specifically on key issues within the HIV epidemic. These are important papers describing various partnerships using CBPR to address key issues within the HIV epidemic.

Manuscript Review Process

Given the special nature of review for this Theme Issue, we want to thank the Peer Reviewers who represented a variety of groups, including community members, organizational representatives, and academic researchers. Reviewers graciously read and reread the manuscripts and provided the authors and the Editors with thoughtful and careful comments, critiques, and suggestions for improvement. Peer reviewers for this Issue included: Robert E. Aronson, DrPH; Thomas A. Arcury, PhD; Tania B. Basta, PhD; Rodger L. Beatty, PhD, LSW; Fred R. Bloom, PhD; C. Alexandra Boeving, PhD; A. Bernard Davis, MBA; Christopher Fisher, PhD; Derek M. Griffith, PhD; Kenneth C. Hergenrather, PhD, MRC, MSED; Keith J. Horvath, PhD; Jami S. Lechlitter, PhD; Willie H. (Billy) Oglesby, PhD, MSPH; Regina McCoy Pulliam, MPH; Robert P. Pack, PhD, MPH; Barry Ramsey, BA; Michael Reece, PhD, MPH; Rhonda Rosenberg, PhD; Aaron T. Vissman, MPH; Leigh Willis, PhD; and Carlos S. Zometa, PhD. Special appreciation also is given to Ms. Cindy Miller, of Wake Forest University School of Medicine, who served as the Managing Editor for this Issue, and Ms. Karen Klein, MA, ELS, of the Research Support Core at of Wake Forest University School of Medicine, for her editorial support of this Introduction.

Conclusions

Since the HIV epidemic began, community involvement has been crucial to identifying priorities and meeting the needs of the most impacted communities. This was long before CBPR was used to describe such partnerships. In the early 1980s community members came together not only to meet the needs of those affected by HIV, but to advocate for action among practitioners, policymakers, and researchers. For example, these community members organized and played a pivotal role in revising the process that the US Food and Drug Administration (FDA) used to test and approve medications for HIV and ensuring that women were included in HIV drug trials. Early activists from the community “pushed” practitioners, policymakers, and researchers. They advocated for the inclusion of those living with HIV/AIDS and those affected (e.g., partners and lovers, biologic families and families of choice, friends, congregations) in decision making, priority setting, research design, and evaluation. They sought out and partnered with health behavior experts and

public health researchers to initiate a process to explore developing effective approaches to understand and intervene upon the psychosocial aspects of the epidemic. Thus, HIV/AIDS has a long history of fostering partnerships among community members, organizational representatives, and academic researchers to impact health and wellbeing of communities and reduce the burden placed by the epidemic.

This Theme Issue is dedicated to promoting the application of CBPR in HIV prevention, care, and treatment, with recognition that considerably more research effort is needed. Although this Issue links CBPR approaches to outcomes, these links are in the nascent stage. Thus, these papers can be viewed as examples, not templates, of CBPR, particularly because a true CBPR approach reflects the local context. Therefore, efforts to codify CBPR would be counter to two of the most salient strengths of CBPR: flexibility and creativity.

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Table 1**Key characteristics and components of successful community-based participatory research (CBPR)****CBPR:**

- 1) Requires a partnership comprised of committed community members, organizational representatives, and academic researchers
- 2) Begins with an identification and exploration of community needs, priorities, and assets
- 3) Includes the multidirectional exchange of information and learning
- 4) Requires openness and trust among partners
- 5) Must promote power sharing among partners
- 6) Ensures that the products of research are shared by partnership members
- 7) Has the potential to increase individual and community capacity
- 8) Supports sustainability, dissemination, and/or the development of next steps
- 9) Is research