Promoting Justice and Reducing Disparities through Community-based, Participatory Research (CBPR) in Detroit, Michigan

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Addressing Health Disparities through Community-Based Participatory Research

CBPR focuses on social, structural, and environmental inequalities through active partnership of community members, organization representatives, and researchers in all aspects of the research process.
Community-Based Participatory Research

- Emphasizes participation in the process of creating knowledge, embodied in constructivist and critical theory paradigms that highlight the socially created nature of scientific knowledge.
Historical Roots of CBPR (Minkler & Wallerstein, 2003)

- Rooted in the belief that traditional “outside expert” approaches to research among complex social problems can lead to disappointing outcomes and ill suited interventions.
- Disillusionment led to a demand for increasing community demand for collaborative research that addresses locally identified issues.
- Involves consciously blurring the lines between the researcher and researched.
Historical Roots of CBPR

- Born from the work of Kurt Lewin (1946) on group dynamics and organizational psychology—action research.
- Believed that involving people affected by a problem in practical problem solving led to better solutions—bringing together stakeholders within an organizational setting.
- Introduced a reflective and cyclical process of fact finding, action, and evaluation.
- Often associated today with utilization-focused approaches that emphasize small group and systems improvement.
Historical Roots of CBPR

- **Participatory action research** (Fals-Borda, 1985) is another branch of approaches that have their roots in popular education and related work by oppressed people in Africa, Asia, and Latin America.
  - Developed as a direct counter to the “colonizing” nature research people were subjected to.
  - Emphasizes emancipatory approaches that challenge positivist research and political domination
  - Influenced by Freire (1970) and Marxist and post-Marxist approaches which viewed social progress through mass participation in challenging inequality and mainstream knowledge production
Historical Roots of CBPR

- **Feminist participatory research, postmodern and post colonial research** are variants of PAR—hearing voices that people’s reality and experiences as a means of understanding power relations.

- Builds on feminist scholarship, where principles include prominent attention to the centrality of gender, race, class, and culture—which influence every aspect of the research process.

- Reinforced structural transformation as the ultimate goal.
Historical Roots of CBPR

- CBPR was born from these movements in the 1990s through the work of such individuals as Israel, Wallerstein, Minkler, Duran, and Eng in Public Health
- Community-based rather than simply community-placed research
- Developed through availability of funding sources for CBPR, including CDC’s urban research centers, of which Detroit was one of the sites.
Key Principles of CBPR

- Recognizes and works to enhance communities of identity
- Builds on strengths and resources within the community
- Facilitates collaborative partnerships in all aspects of research
- Integrates knowledge and action for mutual benefit—information gathered to inform community change efforts
More Principles

- Promotes co-learning and empowering process that facilitates reciprocal transfer of knowledge, skills, capacity, and power
  - Involves a cyclical and iterative process—feedback and reflection
  - Disseminates findings and knowledge gained to all partners—ownership of knowledge is acknowledged
Capacity Building and Civic Engagement

- Strengthens the ability of community organizations and groups to build their knowledge, structures, systems, people and skills so they are better able to define and achieve their objectives.
- Promotes both social and political participation, both formal and informal, organized community life.
- The capacity of people to organize in ways that bring about dialogue with and/or challenge the state, sometimes providing services outside the market.
Successes in CBPR

- Small boom in CBPR funding through federal sources and foundations, somewhat tempered
- Emergence of new NIH study sections, e.g., Community Level Health Promotions (CLHP), Community Based Participatory Research (CBPR), Translational Research
- Increasing national recognition of CBPR from an alternative paradigm to a preferred approach to working with oppressed communities
- Increasing number of publication outlets for CBPR work, e.g., AJPH
Successes in CBPR

- Coincides with increasing national attention to health disparities that emerged from Surgeon General Satcher’s report
- Increasing evidence of positive outcomes, not only in clinical and social outcomes, but satisfaction and recognition from the community that real tangible benefits result from CBPR
- Ability to shift the power dynamics of research including financial resources and decision making power
Remaining challenges of CBPR

- Not a one size fits all model—principles must be adaptive to needs and local contexts—must be owned by and not imposed on partnerships
- Not everyone is going to be involved in the same way—need to clarify roles
- Conflict of interests between researchers and community—need for scholarly publications, grants, etc versus tangible benefits to community, priorities, and political agendas
- Trust is an ongoing issue and must be acknowledged throughout the process
Remaining issues in CBPR

- Time involved in doing CBPR and outlets for dissemination not completely resolved
- Must develop processes and procedures to ensure that CBPR principles are followed
- Sustainability—what happens after the grant ends?
- CBPR is a reflexive process—if we assume that we have achieved it, then we likely have not.
- We need to be open to our own critique and the critique of others and grow from them—requires humility and sense of critical consciousness
Why Use CBPR Approaches To Research?

- Increasing recognition that “traditional” research approaches have failed to solve complex health disparities.
- Community members, fed up with being “guinea pigs”, are increasingly demanding that research address their locally identified needs.
- Major community involvement can lead to scientifically sound research.
- Research findings can be applied directly to develop interventions specific for communities.
- CBPR has the potential to build greater trust & respect between researchers & communities.
Benefits of CBPR for all partners

- Partners gain skills in working collaboratively & in more participatory ways
- Better understanding of each other’s strengths & limitations
- Increased networking & collaboration among the partners leads to support for each other’s work & the establishment of new collaborative efforts
- Community partners & researchers learn from & influence one another
- Learn new ways of thinking about their own work
- Reconsider the appropriateness of the measures & techniques in light of new perspectives
Examples of benefits for institutional partners

- Learn more about local resources & services
- Understand community history, culture & dynamics & how interventions in other communities may or may not apply to local circumstances
- Improve access to funding mechanisms
- See evidence of how community experiences can improve the research process
Examples of benefits for community partners

- Understand institutional history, culture & dynamics & how certain decisions about research design could impact the credibility of the results
- See evidence of how their experiences can improve the research process
- Obtain data that validates their concerns to the “outside world” & provides “proof” that policymakers, the media, & other high-level decision makers require before they believe that the issue deserves their attention
- See resulting benefits in the community
The REACH Detroit Partnership mission is to inform, educate and involve families, communities and health care systems to prevent and manage diabetes.
The REACH Detroit Partnership

- **Community-Based Organizations:** Alkebu-lan Village, CHASS, Delray United Action Council, Friends of Parkside, Latino Family Services, Southwest Solutions, Warren-Conner Development Coalition

- **Health Related Organizations:** Henry Ford Health System, St. Johns Riverview, Detroit Department of Health & Wellness Promotion, Michigan Department of Community Health, and Southeast Michigan Diabetes Outreach Network (SEMDON)

- **Research Centers:** University of Michigan Schools of Social Work, Public Health and Medicine

*Affiliated with the Detroit Community-Academic Urban Research Center (URC)*
REACH Detroit Partnership’s Central Coordinating Organization is CHASS - Community Health & Social Services Center, Inc.
How REACH Detroit Accomplishes Its Mission?

1. Capacity building and change among change agents
2. Increase knowledge/skills of persons with diabetes and households members to change behavioral risk/protective factors associated with diabetes
3. Strengthen knowledge base and increase capacity of health care providers and health care systems
4. Targeted action to increase social support to promote risk/protective behavior change
5. Community system change and change among agents
REACH Detroit Partnership
Origins and Aim

**Origins:** Community concern about diabetes and its consequences

**CDC-funded REACH 2010 Community Action Plan:**
- 1999 planning year built community coalitions and capacity through work groups, focus groups and community meetings
- 2000-2008 CDC-funded interventions

**Aim:** To eliminate disparities in type 2 diabetes, complications and their risk factors among African Americans and Latinos in Detroit
REACH Detroit’s Community Action Plan (CAP)
Family Intervention – Goals

- Improve diabetes self-management care
- Increase physical activity and healthy eating
- Enhance family-provider relationships
- Increase access to community resources
- Increase healthcare consumer skills
Family Intervention – Design

- Phase 1: Legacy of distrust in the community → Non-randomized, 1 group, pre-, post-test design (n=180, cohort 1)

- Phase 2: Increased community trust → Randomized intervention & control, pre-post design (n =164; 87 delayed [control], 77 immediate)

- Phase 3: Need to demonstrate effectiveness with rigor → Randomized controlled trial, enhanced usual care control, pre-post (n=250, 140 intervention, 110 EUC)

CBPR Principle: Integrates and creates a balance between knowledge generation and action for mutual benefit of all partners.
Family Health Advocates: Promoters of Healthy Lifestyles

- Lead 11-session Journey to Health/El Camino a la Salud curriculum
- Conduct home & clinic visits with clients & case mgmt.
- Support client’s behavioral change efforts
- Disseminate information and provide resources
Intervention Effects* on Participants

- Blood sugar control (A1c) within intervention group significantly improved between baseline & post-intervention follow-up. **The A1c drop was 0.8 in the adjusted model.**

- Blood sugar control did not improve significantly in the control group.

- LDL cholesterol dropped significantly within the intervention group, but not the control group.

- No significant changes in blood pressure, BMI, or weight.

*All models adjusted for age at baseline interview, gender, race/ethnicity, and health care site.*
Hemoglobin A1c dropped significantly within the immediate intervention Group, \( p < .01 \). The difference between the drops in A1c between the immediate and delayed groups was statistically significant.
Adjusted Behavioral & Knowledge Outcomes

- The percentage of participants who reported adequate levels of physical activity significantly increased in both the intervention and control groups – from approximately a third to 53%.

- Both groups also increased their average daily fruit and vegetable serving by about half a serving.

- Intervention participants significantly improved their understanding of how to manage their diabetes and their knowledge about relationship between diet, exercise, and blood sugar control.

- There were no significant improvements in diabetes self-management understanding in the control group.
Understanding of Diabetes Management, Mean (s.e.)

Change in Understanding of Diabetes Management, Baseline to 6 Months

-0.5  0  0.5  1  1.5

Delayed  Immediate

Question: “How well do you understand how to manage your diabetes?”,
1 = Not at All to 5 = Very Well. Significant improvement between immediate and delayed arms, p < .01.
People in the immediate intervention improved, relative to the delayed intervention group, in understanding the relation between diet and blood sugar, $p < .05$. 
People in the immediate intervention improved, relative to the delayed intervention group, in understanding the relation between exercise and blood sugar, $p < .01$. 

Knowledge of Exercise and Blood Sugar

<table>
<thead>
<tr>
<th>Strongly Agree That Exercise Will Effect Blood Sugar, %</th>
<th>Baseline</th>
<th>6 Months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delayed (Control)</td>
<td>45.0</td>
<td>47.5</td>
</tr>
<tr>
<td>Immediate</td>
<td>56.7</td>
<td>83.3</td>
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Health System Intervention Goals

- To increase the knowledge and ability of healthcare providers and health systems to provide high quality, culturally competent diabetes care.

- To enhance provider-patient and provider-community relationships
Health System Intervention Outcomes
Community and Social Support

Intervention Goals

- Increase awareness of diabetes and its risk factors
- Increase resources, access and opportunities for physical activity and healthy eating
- Increase social support for healthy lifestyles
Community Level and Social Support Intervention Outcomes
Key Accomplishments

- Developed strong CHW model
- Developed a culturally/linguistically tailored, replicable diabetes self-management and healthy lifestyle curriculum
- Statistically significant improvement in diabetes self-management and health behaviors
Key Accomplishments (cont.)

- Developed process, implemented and sustained group exercise classes
- Increased awareness of health disparities among health care providers
- Conducted diabetes awareness campaigns
- Secured additional grant funding
New support for REACH

- 5-year NIH grant to rigorously test the efficacy and cost-effectiveness of the FHA intervention
- FHA’s will be integrated into health care services at CHASS
- NIDDK Special Emphasis Panel on Translational Research
- Additional grants to support diabetes prevention are pending
New support for REACH (cont.)

- 3-year American Academy of Family Physicians Foundation grant (Peers for Progress) that will test:
  - effective approaches to train peers in state-of-the-art behavioral methods that assist patients to initiate and sustain effective self-management behaviors and work constructively with health care providers; and
  - peer support programs that can be embedded within clinical and community settings to provide long-term support for adults with diabetes.
New support for REACH (cont.)

- 3-year funding from Recovery Act 2009
  Limited Competition: Innovative Adaptation and Dissemination of Agency for Healthcare Research and Quality (AHRQ) Comparative Effectiveness Research Products (iADAPT) program
  - To develop and evaluate a computer tailored online diabetes medication decision aid
  - FHAs will provide patients with poor glycemic control with personalized patient education materials
Opportunities & Challenges

- Growing body of evidence for efficacy of Community health workers (CHW’s)

- REACH Detroit’s success due to integration of CHW’s with FQHC-Health System partnership for primary, secondary and tertiary care

- Sustainability: the challenge! CHW’s work rarely reimbursed or integrated into health care systems

- Advocacy needed to support development and maintenance of reimbursement (insurance, Medicaid, Medicare) for integrated CHW-Health System models; FQHC’s are a great place to start
CBPR benefits the community!
THANK YOU

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Or visit our websites:
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