Health Disparities and Community-Based Participatory Research

Introduction to Principles and Practice of Clinical Research

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Social Determinants of Obesity and Cardiovascular Risk

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Objectives

Introduction to CBPR

Role of CBPR in reduction of health disparities

Case Study:

CBPR work by Powell-Wiley Research Group

The Washington D.C. Cardiovascular Health and Needs Assessment

Types of Community Engagement

Practice-based Research Networks (PBRN)

Community-oriented Primary Care (COPC)

Community-based Participatory Research (CBPR)

Definition of Community-Based Participatory Research

A partnership approach to research

Equitably involves community members, organizations, and academic researchers in all aspects of the research process

Enables all partners to contribute

Enhances a common understanding

Integrates knowledge gained with interventions and policy change

Definitions of Community

Populations defined by geography, race/ethnicity, gender, sexual orientation, disability, or health condition

Groups with common interest or cause

Healthcare or service agencies/organizations

Healthcare or public health providers

Community-based groups with public health concerns

State, local, and tribal leaders and policy-makers

What is the rationale for CBPR?

Increasing demands for community-driven research

Understanding of importance of local and cultural context/external validity

Complex health and social problems ill-suited to “outside expert” research

History of research abuse and mistrust

Disappointing results in intervention research

Interest in research to improve best practices/processes

CBPR Role in Reducing Health Disparities

Communities most affected by health disparities

Develop partnerships with trusted community members

Identify assets of community to improve health outcomes and reduce disparities

Mobilize community resources towards targeting health disparities

Tailor outcomes to specific community needs

Class III Obesity Associated with Greater 30-Day Mortality after STEMI in National Registry

Obesity is a Target to Improve Cardiovascular Health

CV Health Factors

Physical Activity

Dietary Intake

Body Mass Index

Total Cholesterol

Fasting Glucose

Blood Pressure

Cigarette Smoking

Obesity Prevalence Highest in Washington, DC Wards 5, 7, and 8

Key Principles of Community Engagement in CBPR

Be clear about purposes/goals of effort

Become knowledgeable about community

Go into community and build trust/seek commitment among formal and informal leadership

Key Principles of Community Engagement in CBPR

Accept that self-determination is right responsibility of all people who constitute community

Partner to create change and improve health

Recognize and respect community diversity

Key Principles of Community Engagement in CBPR

Identify and mobilize community assets

Release control of actions/interventions to community; be flexible to meet changing community needs

Requires long-term process and commitment

Guiding Principles/Core Values of CBPR

Trust

Respect

Self-determination

Mutuality of interests

Perspective taking

Full participation

Reciprocity

Collective benefit

Long-term commitment

CBPR: What it is and isn't

CBPR is an approach to research

changes the role of researcher/agency and researched

CBPR is not a specific method or set of methods

Can involve qualitative and quantitative methods

Can involve multiple research designs (observational studies and/or randomized trials)

CBPR goal is to influence change in community health, norms, systems, programs/policies

Application of CBPR Approach

CBPR Step 1: Building Partnerships

Self-Reflection

Intentions, capacities, and liabilities

Our institution's strengths and liabilities

Identify Potential Partners

Negotiate Targets for Work

Create and Build Participatory Structures between:

Academia and Community

Principles

Decision-making

Control of budgets and data

Building CBPR Partnerships: Powell-Wiley Group

Self-Reflection

Honest about focus on CV health

Strengths in identifying novel methods for intervention (i.e. mobile health technology)

Identify Potential Partners

One-on-one meetings with community leaders

Presentations to government, advisory neighborhood commissions (ANCs), public health organizations, academia, churches

Required about 1.5 years of work

Community Advisory Board – DC Cardiovascular Health and Obesity Collaborative (DC CHOC)

CBPR Step 2: Identify Research Questions and Methods

Difference between community outreach and CBPR

Where do questions come from: community or academia or both?

Initial participation by Advisory Committee?

Continual participation throughout which informs and changes intervention?

CBPR Step 3: Participatory Data Collection

Participatory process that is most used

Train community interviewers, survey data collectors, focus group facilitators

Job opportunities for community

Enables better response rate

Issues of confidentiality

Hypothesis for Powell-Wiley Research Group

A CBPR approach, including mixed methods (qualitative and quantitative) approaches, would engage community members in Washington, DC to use mobile health technology targeting physical activity and dietary intake as CV health factors.

Clinical Protocol Summary

Clinical Protocol Summary

Mixed-Methods Approach to CBPR

Focus Groups

Recommended by DC CHOC members

Done in collaboration with Wallen Group, NIH CC

Goals of Focus Groups

Focus Group #1: Group-based cognitive interviewing for refining the survey instrument

Focus Group #2: Barriers to use of technological tools (wrist-worn PA monitor, digital food record)

Qualitative Data From Group-Based Cognitive Interview Led to Survey Modifications

Changes made to the survey based on participants' suggestions included:

reformatting physical activity (PA), diet and weight history scales and responses

inclusion of more culturally relevant, community-specific questions related to self-efficacy and health behaviors

Sub-optimal Physical Activity levels Among Most Participants in Pilot Testing

Hypothesis: Community members would be willing to use PA wristbands for activity self-monitoring.

One hub per church used to address:

Socioeconomic and geographic barriers to broadband network and wi-Fi access

Limited access to computers

Restricted smartphone data plans for use of mHealth devices

Limited technology literacy

Data Collection Logistics

CBPR Step 4: Participatory Data Analysis

Role of University expertise:

Statistical programs (Quantitative/Qualitative)

Present data in useable form for interpretation

Train community members

Role of Community expertise:

Provide interpretation of importance that only possible if from locality (local research team/advisory committee)

Protection of community

Enrolled Population from Contiguous Geographic Area

100 participants

79% women

99% African American

48% D.C. residents

80% from Wards 5, 7, 8

44% from Prince George's County (adjacent to target D.C. wards)

Use of PA Monitoring System in Community Appears Feasible

PA Monitor Users are of lower SES than PA Monitor Non-Users

PA Levels Can Be Target for Intervening on Obesity in the Community Population

CBPR Step 5: Participatory Dissemination

Accountability to communities and to community protection

Community reports (print/videos/etc)

Academic publishing issues (especially for junior faculty)

Wallerstein, N., Duran, B., Minkler, M., Foley, K., Developing and Maintaining Partnerships,

Methods in Community Based Participatory Research, Israel, B., et al (eds). San Francisco, Jossey Bass, 2005

Dissemination Efforts: Powell-Wiley Group

Early dissemination of focus group data

Evaluated community organization for dissemination

Identified preferred methods for data dissemination to community

Data briefs and newsletters for partnering churches and community advisory board

Presentations in community

Abstracts and publications

Challenges in Researcher-Community Relationships

Nuances of participation and community consent (who is participating/who is not)

Power and privilege: Who sets the research question? Who has power of knowledge?

Historical research abuse/stereotyping/racism

Be willing to face the reality of negative history

Challenges in Researcher-Community relationships

Academic vs. community time: publishing versus taking action

CBPR cyclical and iterative process: research goals are not always known at the beginning of work

Research team having necessary skills, ie., cultural humility, listening, sharing decision-making

Benefits of CBPR

Enhances relevance of research questions to the communities at highest risk

Enhances reliability and validity of measurement instruments

Improves response rates

Enhances recruitment and retention

Strengthens intervention by incorporating cultural beliefs into scientifically valid approaches

Benefits of CBPR

Increases accurate and culturally sensitive interpretation of findings

Facilitates effective dissemination of findings to impact public health and policy

Increases translation of evidence-based research into sustainable community change

Increases research trust

Provides resources and benefits to communities

Joins partners with diverse expertise

Future Directions: CBPR in Powell-Wiley Group

Increase community members' involvement with community advisory board

Development of new methods for dissemination

Intervention targeting physical activity

Use of mobile health technology

Tailored messaging to neighborhood resources

Focus on Wards 5, 7, 8 and Prince George's County

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