Implementation Research and Community Engagement: Opportunities and Challenges of Community-based Participatory Research (CBPR)

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“It takes 17 years to turn 14 percent of original research to the benefit of patients

Balas and Boren, 2000”
Objectives

- Describe the essential components of implementation research
- State the major challenges of implementation research
- State the essential elements and challenges of engaging community organizations in research
- State the components of the RE-AIM evaluation model
Chronic Care Model
Implementation Research in Health

- the scientific study of methods to promote the systematic uptake of research findings and other evidence-based practices into routine practice, and, hence, to improve the quality and effectiveness of health services.

  – Eccles and Mittman, 2006
Dissemination vs Implementation

- **Dissemination** - the targeted distribution of information and intervention materials to a specific audience
- **Implementation** - the use of strategies to adopt and integrate evidence-based health interventions and change patterns within specific settings.”
Challenges

- Variability of intervention across time and space
- Variability of the implementation across time and space
- Strong contextual influences (leadership, staff, experience, budget, culture and values)
- Effects weak rather than robust
Community Based Participatory Research
Variations on the theme

- Participatory action research
- Participative research
- Conscientizing research
- Policy-oriented action research
- Empowerment evaluation

- Collaborative inquiry
- Dialectical research
- Emancipatory research
- Social reconnaissance
- Participatory learning research
- Participatory rural appraisal
Benefits of Using a CBPR Approach

- Provides resources for communities involved
- Joins partners with diverse expertise to address complex public health problems
- Increases trust and bridges cultural gaps between partners
- Has potential to translate research findings to guide development of further interventions and policy change
Definition of CBPR

- Contemporary Definition of CBPR

“A Partnership approach to research that equitably involves community members, organizational representatives and researchers in all aspects of the research process” Israel, BA et al. (2001)
The “P” in CBPR: Implications for Public Health

- Conventional research *in* communities vs. CBPR research *with* communities

- Core Tenets of CBPR
  
a. “Shared ownership of research projects”

b. Community-based analysis of public health issues

c. An orientation toward community action
COMMUNITY IGNORED
COMMUNITY PLACED
COMMUNITY INFORMED
COMMUNITY AS PARTNERS
Narrow VS. Broad Definition of CBPR

Narrow
- Research idea originates in the community
- Community involved in all aspects of the research process
- Roles identical for all projects

Broad
- Research embraced by the community as a priority
- Community has active role in the research (e.g., refining objectives, establishing data collection approaches and materials, interpreting results, and disseminating results)
- Roles vary; community rep among the leadership
Principles of CBPR

- Community as unit of identity
- Builds on strengths within the community
- Facilitates a collaborative partnership: leadership, control
- Fosters co-learning and capacity building

- Integrates and achieves a balance between research and benefit
- Focuses on the local relevance of public health problems
- Applies a systems approach to the partnership
- Disseminates results
- Commitment to sustainability

Minkler and Wallerstein, 2008
Pathways to Palliative Care: a Church-based Model
Research on Ethnicity and EOL

- About 8-9% of persons on hospice in US are African American.
- African Americans are more likely to prefer life sustaining care.
- African Americans report less knowledge about hospice and less use of advance directives.
Research on Ethnicity and EOL

- African Americans are more likely to have spiritual beliefs that conflict with the goals of palliative care, and to distrust the healthcare system.
- Physician preferences for end of life treatment vary by race.
- Hospice eligibility criteria may disproportionately exclude African Americans.
Research Literature on AA and EOL Care


Project Goal and Aims

- Engage AA churches as active participants in reducing the suffering of individuals at the End of Life
- Conceptual Framework: improving communication using the church as a venue will lead to acceptance of PCH and reduced suffering, and improved care of persons with life limiting illnesses
  - Change the culture of the church by engagement (multimedia approach) of church leaders and congregants
  - Train community health workers as comfort care supporters based in churches in the Philadelphia area
Getting Started

- Identify appropriate community partners?
- Individual church approach
  - Meetings with pastor and another committed advocate in each of five churches (four Baptist and one AME)
  - Meetings with leadership of ministries
Focus Group

- Focus Groups- 7 groups in 2 churches (n=51)
- Selection of attendees
  - Church leadership - deacons and deaconesses
  - Members of health ministries
  - Comfort and bereavement ministries
  - Other church members
Focus Group Findings

- Consensus that support needed in 5 areas
  - Faith aspects of death and dying
  - Emotional Issues
  - Family dynamics
  - Facts and Myths About palliative care and hospice
  - Communication with health professionals
Implementation: Feasibility

- Comfort care supporters training curriculum
  - Classroom component (eight modules) - 27 hrs
  - Visitations to persons in the church with life-limiting illnesses

- Impact on church culture and attitudes
  - Pastors - interviews
  - Other leaders (e.g., Deacons):
  - Congregation – digital and print
Evaluation Considerations
Evaluation Framework

- Two very different questions
  - 1. Does it work? Is it “effective”?
  - 2. How, why, when and where does it work? *How should I use it? How do I make it work?*
Evaluation – RE-AIM

- **Reach**
  - Learners selected, attendance, satisfaction

- **Effectiveness**
  - Knowledge and Skills of learners

- **Adoption**
  - Leadership participates, congregation embraces

- **Implementation**
  - Structure of church, staff roles, ministry roles

- **Maintenance**
  - Next Stage
Generic Challenges of CBPR

- Different organizational values
- Distrust *(cultural and language barriers)*
- Need for a research question vs a demonstration project
- Significant time required to develop positive relationships
- Personalities and styles
- Funding Challenges: “show me the money.”

Challenges and Barriers - Palliative Care Project

- Maintaining the partnership focus on research
- Selecting the comfort care supporters
- Identifying persons with a life limiting illness:
  - Functional impairment, wt loss and anorexia or objective evidence of metastases
- Logistics and supervision during the field training
Summary

- CBPR is a distinct process not a research method
- It is a partnership with shared leadership and funding
- Both parties derive mutual benefits
- Utilizes the strengths and skills of the community as an integral component of the research
- Primary goal is to ensure a benefit after the project has ended

……...but one size does not fit all projects