Community Empowered Research Training: Some thoughts about research methodology

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A view from the ivory tower

- Historically, researchers have been academics
- Enormous gains in knowledge
- Basic vs applied research in the sciences
- Funding basic and applied research
Impetus for change

- Gains from ‘traditional’ research and funding
  - Extensive knowledge base; breakthroughs in diagnostics; health indices; effective therapies etc.
  - Significant impact on increased life expectancies
- No appreciable effect on health practice
- Health disparities remain even when access issues are taken into account
- Spending disparity: Poorer countries that spend less on health care are in better health than US


Roots of change

Kurt Lewin: 1940’s

- ‘action research’: research not just to understand phenomena, but also to be able to shape it
- Address and redress social inequalities
- Challenged traditional concept of ‘scientific objectivity’
- Rejected idea that researchers had to remove themselves from the community in order to study it
Paulo Friere

- Education is a dialogue … conversation
  - co-operative activity that involves respect and exchange.
  - "Banking" metaphor
- Praxis: action and making a change in the world. Not one person acting on another, but with another
- Conscientization - developing consciousness, that has the power to transform reality.
- Situating action in the lived experience of the individual
Many non-clinical factors contributory to disease process not traditionally seen as part of research

Prevention and control of disease: social/cultural, political, environmental conditions are complex contributors

Diagnosis: a process of ‘acculturaion’

Maintenance: health as a sustainable process

Doing research IN a community is different from doing WITH a community

Took a long time for ‘revolutionary’ ideas to gain traction with medical and research community
Hypertension: An example

- Prevalence of hypertension increasing despite slew of research studies about hypertension management
- Uncontrolled cases account for two-thirds of those diagnosed
- Some populations more intensely treated, yet more poorly controlled
- Access: medical and environmental
All politics is local.....

Thomas “Tip” O’Neill
How is this related to methodology?

- Fundamental assumptions about the correlation and causal relationships that undergird the issue under investigation IS what guides methodology.
- Fundamental shift in assumptions: centrality of role of community and communal factors
- Research shift: from “knowing” to combining knowledge with **action** to achieve social change
Research WITH vs IN

- Recognition of community as a distinct social entity with a sense of identity and shared life rather than as a physical location or setting.
- Recognition of the importance of social, political, cultural, and economic systems to health behavior and outcomes.
- Engages community members in choosing and developing research topics, data collection, and interpretation.

Adapted from Viswanathan et al (2004) AHRQ Publication #04-E022-2
Translating assumptions into principles that guide research

- Recognizes community as a unit of identity
- Builds on strengths and resources within the community
- Facilitates collaborative partnerships in all phases of the research
- Integrates knowledge and action for mutual benefit of all partners
- Promotes a co-learning and empowering process that attends to social inequalities
- Involves a cyclical and iterative process
- Addresses health from both positive and ecological perspectives
- Disseminates findings and knowledge gained to all partners

http://www.cbprcurriculum.info/
Consequence on Methodology

- Emphasis on qualitative as well as quantitative methodologies
- High priority on translation of basic, intervention, and applied research into changes in policy and practice.
- Change assessments need to be built into design of study

Adapted from Viswanathan et al (2004) AHRQ Publication #04-E022-2
Community Engagement and Research Methodology

Community can be involved at every level: “it’s never too early, never too late”

- Select research question
- Develop proposal
- Financial responsibility
- Study design
- Recruiting and retaining subjects
- Participate in design of instruments and data collection
- Develop intervention
- Interpret and disseminate findings
- Apply findings: translate research to practice
QuickTime™ and a decompressor are needed to see this picture.
Study Types

Basically two types:

- Interventional:
  - Health is Strength: Korean American (1997)

- Non-interventional:
  - Health promotion for South Asian women (2002)
  - Identifying older Chinese immigrants at high risk for osteoporosis (2003)
Study Design

- Experimental (RCT)
  - Participants randomly assigned to groups
- Quasi experimental
  - Comparison of identified populations
- Nonexperimental
  - Qualitative data
  - Correlational data
  - Training, workshops, educational programs, etc.
Strengths and Challenges: Strengths

“Lack of fit” between traditional methods of research and community-based versions: both a strength and challenge.

Strengths:
- Increased participation
- Increased external validity: generalizability
- Decreased attrition
- ‘action-based’:
- Increased community capacity
- ANRQ study: no trend towards correlation of community involvement and rigorous research methodology

Challenges:

- Not all researchers receptive or trained in methodologies required for community-based approaches
- Not all review panels receptive to ‘community based approaches’
- Time:
  - Building relationships take time
  - Length of funding: typical funding cycles 5 yrs.
- Role of publications:
- Does the community always come up with the ‘strongest’ designs?
Some last thoughts

“Spillover” effects

- Loss of internal validity: biased recruitment or selection
- Loss of randomization: communication between comparison and control groups
- Loss of external validity: highly motivated intervention groups
- Biased interpretations