Community Based Participatory Research as a Path to Equity: Role of Research Teams, Researcher Identity and Mentorship

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CBPR on the Rez: Reflections on the Rocks

- CBPR as Translational Science
- Reflections on CBPR Identity
- Reflections on Mentorship
- Living with Contradictions in Research Partnering
How does Power and Privilege from our Identities affect CBPR Research?
My Research Story

- Paulo Freire Popular Education (1970s -- )
- Empowerment Research (1980s -- )
  - Adolescent Social Action Program with Native and Latino Communities, YouthLink, Women to Women
- Community Based Participatory Research: 1990s
  - Participatory Eval. NM Healthy Communities/Councils
  - PAHO Participatory Evaluation in Latin America
- CBPR Research with Tribes
  - National Healthy Native Community Fellowship
  - New Mexico CBPR Intervention Tribal Research
- National CBPR Process & Outcomes Research
My Starting Points

“For apart from inquiry, apart from the praxis, individuals cannot be truly human. Knowledge emerges only through invention and re-invention, through the restless, impatient, continuing, hopeful inquiry human beings pursue in the world, with the world, and with each other.”

Without a sense of identity, there can be no real struggle…”

— Paulo Freire, *Pedagogy of the Oppressed*
Challenge of Inequities

Inequities widening dramatically

Reducing inequities central to both:
Social Epidemiology
CBPR / Community-engaged intervention research

Social determinants of health → ? → Health equity outcomes
Challenge of Translational Science

- Challenge of bringing Evidence to Practice
  - Internal validity insufficient for translational research
  - External validity: Implementation/role of context

- Challenge of what is *Evidence*
  - Evidence-Based Practice vs.
  - Cultural-/Community-/Practice-Based Evidence

- Challenge of Scientific Knowledge Production *Itself*
  - Reinforcing Unidirectional Translation

Challenge of Research Abuse and Mistrust
Challenge of Research History:
Tuskegee Syphilis Experiment

"The United States government did something that was wrong, deeply, profoundly, morally wrong. It’s an outrage to our commitment to integrity and equality for all our citizens... clearly racist." President Clinton's apology for the Tuskegee Syphilis Experiment to the eight remaining survivors, May 16, 1997

Peter Buxtun, a former Public Health Service employee.

Tuskegee Institute
Challenge of Public Health History

- Health Education and the marginalization of culture
- Native agency and voice erased
- Calls for collaboration with everyone, except Navajos...

Challenge of Current Abuse

Havasupai Tribe files $50M lawsuit against ASU
The Havasupai Tribe has filed a $50 million lawsuit against Arizona State University, the Arizona Board of Regents and three researchers alleging that blood samples taken from tribal members under the pretext of diabetes research were destroyed, lost or used in studies of schizophrenia, inbreeding and population migration without the donors' consent.

Arizona lawsuit over misuse of Havasupai blood samples dismissed 5-4-07
A judge has dismissed a lawsuit against the University of Arizona, Arizona State University and researchers claiming they misused blood samples from Havasupai Indian tribal members.
Community Based Participatory Research (CBPR)

“Collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities.”

W.K. Kellogg Community Scholar’s Program, 2001

NM CARES Health Disparities Center, 2011
Community Based Participatory Research as Opportunity

- Can we use CBPR partnership opportunities and *research spaces* for:
  - Regaining research trust
  - Co-construction of knowledge:
    - academic and community knowledge
    - Purpose of promoting equity and social justice

- Need Accurate and Valid Data
- Need Constituents to Demand Change

What is role of research teams and researcher identities for effective partnering for change?
Our Team Inquiry

• Literature on Identity and Positionality
• Team Panel: UNM CBPR 2011 Institute: Indigenous and Critical Methodologies
• Ongoing Reflections on our Research

How do we perceive the role of our identities in doing CBPR?

How do we perceive the role of mentorship?
   What motivates each of us to work in the team?
   What has kept us connected and wanting to continue with the team?
Research Identities in CBPR
University Institutional Contradictions in Creating a Diverse Team

- Democratic Team
- Privilege to be an Academic:
- Freedom of Voice / Value of Diversity
- Expectation that my voice is heard

Hierarchy of Universities

- University Norm of Objective Inquiry /
  Standard for how to do Science
- Scholars of color often not experience being heard / outsiders–within

Allen, B., Orbe, M., Olivas, M. 1999, “The Complexity of Our Tears: Dis/Enchantment (In)Difference in the Academy, Communication Theory,
Research Contradictions of Power and Privilege based on Identity

- Positions of Power between Researchers and Researched
- Processes of Research: Decision-making, etc.
- Representation and Writing: Who has Voice
  Diane Wolf, *Feminist Dilemmas in Fieldwork*, 1996

- Access to Knowledge: who has access to what knowledge?
Jemez Pueblo
- Less than an hour North of ABQ

Ramah Navajo
- Two hours West from ABQ
Family Listening Program

1. Welcoming
2. Family Dinner
3. Our Tribal History
4. Our Tribal Way of Life
5. Our Tribal Vision
6. Community Challenges
7. Communication & Help Seeking
8. Recognizing Types of Anger
9. Managing Anger
10. Problem Solving
11. Being Different
12. Positive Relationships
13. Building Social Support
14. Making a Commitment
“Research for Improved Health” Study of Community–Academic Partnerships

- **Funding:** NIH: NARCH V: 2009–2013
- **Partners:**
  - National Congress of American Indians Policy Research Center
  - University of Washington and University of New Mexico
- **Aims:** To advance science of CBPR to improve equity
  1. Describe variability of CBPR processes and outcomes across partnerships
  2. Describe and assess the impact of governance across AI/AN and other communities of color
  3. Examine associations among group dynamic processes and CBPR outcomes
  4. Identity promising practices and tools
Agencies

University

CBO's

Community

Structural Dynamics

Individual Dynamics

Relational Dynamics

Group Dynamics & Equitable Partnerships

Intervention & Research

Fits Local/Cultural Beliefs, Norms & Practices

Reflects Reciprocal Learning

Appropriate Research Design

Outcomes:

System & Capacity Changes

Policy/Promises

Sustained Interventions

Changes in Power Relations

Cultural Renewal

Improved Health

Disparities

Social Justice

Contexts

Socio-Economic, Cultural, Geography & Environment

National & Local Policies/Trends/Governance

Historic Collaboration: Trust & Mistrust

Community Capacity & Readiness

University Capacity & Readiness

Health Issue Importance

Group Dynamics

Structural Dynamics:

- Diversity
- Complexity
- Formal Agreements
- Real power/resource sharing
- Alignment with CBPR principles
- Length of time in partnership

Individual Dynamics:

- Core values
- Motivations for participating
- Personal relationships
- Cultural identities/humility
- Bridge people on research team
- Individual beliefs, spirituality & meaning
- Community reputation of PI

Relational Dynamics:

- Safety
- Dialogue, listening & mutual learning
- Leadership & stewardship
- Influence & power dynamics
- Flexibility
- Self & collective reflection
- Participatory decision-making & negotiation
- Integration of local beliefs to group process
- Task roles & communication

Intervention

- Intervention adapted or created within local culture
- Intervention informed by local settings & organizations
- Shared learning between academic & community knowledge
- Research & evaluation design reflects partnership input
- Bidirectional translation, implementation & dissemination

Outcomes

CBPR System & Capacity Changes:

- Changes in policies/practices
  - In universities & communities
- Culturally-based & sustainable interventions
- Changes in power relations
- Empowerment:
  - Community voices heard
  - Capacities of advisory councils
- Critical thinking
- Cultural revitalization & renewal

Health Outcomes:

- Transformed social/econ conditions
- Reduced health disparities

CBPR Conceptual Logic Model

CBPR Conceptual Logic Model

- Social-economic, cultural, geographic, political-historical, environmental factors
- Policies/Trends: National/local governance & political climate
- Historic degree of collaboration & trust between university & community
- Community: capacity, readiness & experience
- University: capacity, readiness & reputation
- Perceived severity of health issues

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Contexts
Intervention
Outcomes

Agencies
University
CBO’s

Structural Dynamics
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Group Dynamics & Equitable Partnerships

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Reduce Health Disparities
Impact of my identity on New Mexico Research

Contradictions of My Identity and history:

Authority & Power means Responsibility/
  Accountability: in research & community benefit
Reputation of PI Matters
Resources and Brokering in Community/Show Up

Subject to Tribal Sovereignty:

  Community Authority/Ownership of Research
Respect Community Knowledge (what is shared with
  me, with bridge team members, or not shared)
Challenge University Policies/Practices
Researcher Identity in National CBPR Study

Impact on Case Study Teams (Who)
- How we divided ourselves for different sites
- Role of PI: Important to show respect by showing up
- “Bridge people” critical

Impact on Research Fieldwork/Data Collection
- Impact on what we heard/access to knowledge

Impact on Data Interpretation/Representation
- Impact on what and how we can interpret
- Impact on ownership of data and co-publication
- Impact on action
Team Voices: Identity

Michael Muhammad

Greg Tafoya

Dr. Lorenda Belone
Current Attacks on Culture and Identity

Mexican–American Studies suspended: Tucson, AZ
7 banned books:
◦ Pedagogy of the Oppressed by Paulo Freire
◦ Chicano! History of Mexican–American Civil Rights Movement by F. A. Rosales

12-year old Menominee Seventh Grader Suspended for Saying "I Love You" in her Native Language
Traditional Mentorship in Research

A personal developmental relationship in which a more experienced or knowledgeable person helps a less experienced or less knowledgeable person.

Mentoring is informal transmission of knowledge, social capital, and the psychosocial support perceived by the recipient as relevant to work, career, or professional development.

- Wikipedia
My History of Mentorship

- Distant Mentors: Paulo Freire and Myles Horton
  - Listening and Dialogue
  - Participatory Learning
  - Social construction of knowledge
  - Self and collective reflection

- UNM School of Medicine:
  - Senior colleagues who had my back
  - Colleagues of color
  - Southwest Addictions Research Group (SARG)
Southwest Addictions Research Group (SARG)

Mentorship

- Technical AND Cultural-Psycho-Social Support
- Bidirectional knowledge
- Community engagement/CBPR

Setting
Mentorship core
Outcomes

Mentor, mentee & community input

Culture & community as foundation
Mentorship with UNM Team

- Ongoing reflection through long rural drives (laptop notes)
- Team longevity
- Believe people are “bigger” than they might believe (L.Moore)
- CBPR Model development and importance of identity in case studies

- Team: Up, Down, Co–Mentorship:
  - How we create Safety to question and be ourselves
  - Recognize structural barriers
  - Intentional co–mentoring
- Community mentorship
Team Voices: Mentorship

Julie Lucero  
Dr. Magdalena Avila  
Greg Tafoya
Reflections on CBPR Teams and Identity

- Purpose of CBPR Research: To facilitate knowledge development that changes social determinants/enhances equity and justice

- Need Accurate and Valid Data
  - Knowledge generated with community
  - Diverse team members critical

- Need Constituents to Demand Change
  - Internal within University
  - External within Communities and Society
  - Trust within partnerships important
What is problem from each point of view?
What should be done from each point of view?
What can we do together?  

Mohan Dutta
Can’t do CBPR in Indian Country without bridge team members, yet important PI role as outsider

Challenge power and privilege, yet benefit from it

Support community autonomy and capacity, yet university can re-colonize

Want to decolonize research and privilege community knowledge, yet danger of misappropriating cultural knowledge

Key: Intention and self–reflexivity, deep listening; belief in hybrid community and academic science
"Deep learning involves the whole body, blood and bone, not just the theoretical or cataloguing of insightful facts and analyses. Deep learning moves the feet to walk in a new way, moves the eyes to see from the new perspective won by that walking, and moves the hands to fashion the tangible world into a new image envisioned by the new seeing."

Humility and Gratitude

Self-reflexive of own positionality

Deep Listening to cultural perspectives of team

“A life long commitment to self evaluation and self critique” to redress power imbalances” Tervalon & Garcia, 1998

Cultivate gratitude
Not all who wander are lost
— J.R.R. Tolkien
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