Basic Principles and Applications of Community-Based Participatory Research to Advance Nursing Science in HIV Prevention

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Greetings from UCLA & Los Angeles
Content Overview

• **What** is CBPR?
  • Definitions and distinctions
• **Why** consider a community-academic partnership in research or special projects? (rationale)
• **How** is CBPR conducted?
  • basic principles
• Considerations for building community-academic partnership and Advisory Boards
• Challenges and Opportunities
• Case Illustrations (Drs. Koniak-Griffin & Nyamath)
What is Community-Based Participatory Research (CBPR)?

• Community-based participatory research (CBPR) is a collaborative process that equitably involves members of the “target” community and/or research participants in the entire research process.

  (Israel et al., 1998, 2005)

• Term CBPR often used interchangeably with community partnered research, community engagement, PR, PAR, collaborative research, although some distinctions exist.
Partnering With Community: Historical Grounding in Nursing
(Henry Street Settlement)

- Started in 1893 by Lillian Wald, this community-based institution still provides services for low-income residents in New York City.
- Focused on care for women, children & poor.
- Partnering with communities is an approach to promote social justice & eliminate health disparities.
- CBPR approach recommended by CDC and IOM.
What Does a Partnership Really Mean?

- Joint Planning and Goal Setting
- Establishing Responsibilities & Authority
- Sharing Results & Rewards
- Sharing Work Effort

Community

Partnership

Academic
Why Consider Using a CBPR Approach?

- Community partners have “unique” expertise
- Direct interactions with community-based organizations & individuals they serve enhance understanding about health issues
- Inherent strengths and rich resources within communities
- Lead to insights about people & potentially effective, culturally centered interventions
Why Consider Using a CBPR Approach?

- Overall quality of research may be improved
  - Increased validity - culturally & linguistically sensitive approach for recruitment/retention, design/review of interventions & measures
- Research more likely to be accepted by people
- Potential sustainability of programs
- Capacity building for all involved
Community Partnerships and Participatory Research*

**Traditional Research**
- Researchers swoop into a community and temporarily work with CBOs to do project (gain access to participants and programs) and then leave
- Project planned, implemented and evaluated by academics
- Results not shared
- Little or no direct benefit to community

**CBPR**
- Mutually beneficial
- Shared power and ownership
- Tailored for community
- Potential sustainability
Principles of CBPR (Israel et al)

- Recognizes the community as a unit of identity – goals, strengths, capabilities, limitations
- Builds on strengths and resources within a community
- Facilitates a collaborative, equitable partnership in all phases of research
  - identifying a specific purpose or problem that partners want to address collaboratively
  - agreeing upon mission, values, common goals, measurable outcomes, and accountability for the partnership

Israel et al., 1998, 2005; Flaskerud & Anderson, 1999
Principles of CBPR (Israel et al)

- Involves an empowering and power-sharing process that attends to social inequities
- Fosters co-learning and capacity building among all partners
- Integrates and achieves a balance between knowledge generation & intervention for mutual benefit of all partners
- Focuses on the local relevance of public health problems and ecologic perspectives that recognize and attend to the multiple determinants of health

Israel et al., 1998, 2005; Flaskerud & Anderson, 1999
Principles of CBPR (Israel et al)

- Involves systems development using a cyclical and iterative process
- Disseminates results to all partners and involves them in the dissemination process
  - sharing outcomes and ownership
- Building community capacity, confidence, and resources (Desired outcome)
- A long-term commitment to sustainability

Israel et al., 1998, 2005; Flaskerud & Anderson, 1999
CBPR requires a major paradigm shift.

- Roles assumed by partners depend upon
  - objectives and organization of project
  - skills of researcher and community partners
  - how much participation community wants
- CBPR studies may employ quantitative, qualitative, or mixed methods
- Qualitative methods are particularly appropriate for intervention development, designing and evaluating measures
- CBPR is appropriate for clinical trials

Israel et al., 2005; Minkler, 2004
**COMMUNITY PARTNERSHIP MODEL**

**Socioeconomic/Cultural/Political and Physical Macro Level Environment**

**Research Participants**
- Community Members
- Advisory Board Members
- Community Research Associates

**Micro Level Participatory Collaboration**

**Establish Mutual Trust, Respect & Partnership**

**Partnership Phases**
- Pre-engagement,
- Engagement,
- Community Assessment,
- Intervention Design,
- Implementation, Evaluation, Dissemination, Sustainment,
- Community Self-Advocacy For Needed Policy Change

**Nurse Scientists and Interdisciplinary Researchers**

Cultural Beliefs, Health Care Foundations

Cultural Beliefs, Knowledge, Strengths

Establishing Collaborative Partnerships: An interactive process
Considerations for Improving Community-Academic Partnerships

• Value community "resident experts"
• Establish Community Advisory Board
• Understand how to collaborate and build effective relationships
  - Commitment = time
  - Patience
  - Respectfulness
  - Flexibility
  - Acceptance
  - Physical presence
Considerations for Improving Community-Academic Partnerships

- Do not enter into partnership with assumptions
- Recognize the existence of competing agendas – be open, respectful
- Meetings: establish ground rules, alternate sites, consider community and academic co-chairs
- Develop a “Memorandum of Understanding” to define partnership roles around key issues e.g., process/ procedure, time parameters
Community Advisory Boards

- Representation from community (CBO and “grass roots”) and academic institution
- Establish a co-leading, co-teaching, co-learning format for meetings and events (Israel et al., 2005)
- Mutually determine ground rules, agendas, minutes
- Engage members and leaders in decision making
- Assure transparent decisions and methods so everyone understands
- Seek consensus but tolerate differences in opinion
Community Partnerships and Participatory Research*

UCLA School of Nursing, Center for Vulnerable Populations Research

- Nancy Anderson, RN, PhD (UCLA)
- Jacquelyn H. Flaskerud, RN, PhD, FAAN
- Janna Lesser, RN, PhD, (UTHSCSA)
- Adeline Nyamathi, RN, PhD (UCLA)
- Carol Pavlish, RN, PhD, FAAN (UCLA)
- Community Collaborators
HIV Prevention for Teen Fathers and Mothers: A Collaborative Approach

Barbara Kappos
Jerry Tello
and others

Deborah Koniak-Griffin
Janna Lesser
Rong Huang

University AIDS Research Program
Background

- Unplanned meeting of the potential partners who recognized the benefits of a community-academic partnership
  - Differing backgrounds & clinical/research experiences
    - UCLA team - adolescent pregnancy/motherhood risk reduction
    - Community partner - Latino health & fatherhood role development
  - Both partners committed to improving the lives of young parents
• Community input needed for development of culturally relevant and effective interventions

• Mutual recognition that HIV transmission was a threat to young parents, particularly those of Latino background

• Grant application submitted in response to continuing high rates of HIV/AIDS among adolescents and young adults
  • 50% of new HIV infections worldwide among people ≤ 25 years
  • HIV disproportionately affects ethnic/racial minorities & women
  • Majority of cases in young women acquired through sexual transmission
• Growing body of literature documenting the strengths and resiliency of young parents
• Lack of couple-focused HIV prevention interventions for any youth & very limited research with heterosexual adult samples

Koniak-Griffin et al., 2008
Purpose of Community and Academic Collaboration

- To develop and test the feasibility of a couple-focused HIV prevention program
  - relevant to the needs of inner-city Latino teen parenting couples
  - realistic for implementation in community settings
- Two phase CBPR project:
  - Phase 1 - Qualitative – examining young men’s feelings related to fatherhood as a potential motivator for risk reduction; development of curriculum
  - Phase 2 – Pilot testing intervention
Phase I: Qualitative

- Focus groups & individual interviews with 45 young Latino fathers, 15-25 yrs old
- Findings – Themes identified
  - A childhood entrenched in poverty, social oppression, violence, and alcohol and drug abuse
  - The role of the gang
  - Taking on the paternal role
    - Leaving the gang
    - Gaining empathy for others
    - Modifying perspective on male-female relationships
- Development of curriculum

Lesser, Tello, Koniak-Griffin, Kappos & Rhys, 2001
Phase II: Research Design

- A quasi-experimental longitudinal design with a 6 month follow-up
- Treatment group - 12-hour program presented in 6 sessions
- Control group – 1 session, general information on HIV/AIDS
- 98 participants (49 couples)
- Feasibility of implementation and evaluation examined
  - Identifying recruitment and retention challenges
  - Making decisions re: sample size for future outcome evaluation
Curriculum

- Curriculum developed based on integration of each partner’s expertise
  - Tello’s framework for practice, “Healing the Wounded Spirit”
  - Specific HIV prevention activities from Project CHARM
  - Findings from Phase I

Lesser, Verdugo, Koniak-Griffin, Tello, Kappos, & Cumberland (2005)
Curriculum

• 12-hours, culturally-tailored (6 sessions)
  – Builds on feelings of maternal and paternal protectiveness as behavior motivator
  – Integrates traditional or cultural teachings (e.g., storytelling)
  – Male-female relationships
  – Cultural values – respect, dignity, trust and love
• Co-led by one male and one female facilitator

Lesser, Verdugo, Koniak-Griffin, Tello, Kappos, & Cumberland (2005)
Findings and Conclusions

- Probability of unprotected sex was reduced & intentions to use condoms was increased significantly in the intervention group
- AIDS knowledge improved in both groups
- Intervention well accepted by inner-city young parents and realistic for adoption in community

Clinical Trial

- Larger scale RCT subsequently conducted to test the efficacy of the intervention (NINR 1-RO1-NR049572000-2007)
  - Similar positive findings with larger sample (n=332)
- Couple-focused HIV prevention program selected as Evidence-based Model by U.S. government
Confronting Health Disparities through Participatory Action Research Among Indian Women With AIDS

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Benissa E. Salem, RN, MSN, PhD  
*University of California, Los Angeles*

National Institutes of Mental Health  MH82662 – R34
Improving ART Adherence Levels and Life of Rural Indian Women Living with AIDS

NIMH R34  2008-2011
HIV/AIDS is a Continuing Challenge

The prevalence of HIV in Andhra Pradesh is higher than that of the nation of India as a whole.

Pandey et al., 2009
Impoverished Women in India at Risk for HIV/AIDS

- Around 2.5 million people living with HIV/AIDS in India
- One third are women of childbearing age
- Rates of HIV are increasing among women whose spouse have high-risk behavior
Challenges Experienced by Women Living with HIV/AIDS in India

- Lack of sexual decision-making
- Lack of knowledge about HIV transmission
- Primary caregiver of ill husband and children
- Little or no time to devote to their own health care
Collaborative Community-Partnered Inquiry

- Emerges from the community.
- Uses members from the targeted group to design the program, convey the message, act as advocates, evaluate and disseminate research.
Cultural Competency

• Set of congruent behaviors, attitudes, and policies that come together amongst professionals and enables those professionals to work effectively in cross-cultural situations (Cross et al., 1989).

• Knowledge, sensitivity and collaboration are fundamental to the development of cc research.
Methods

Design
A site randomized control trial of 68 Women Living with AIDS in rural Andhra Pradesh to one of two arms for a six month intervention:

– Asha-Life (AL) intervention (n = 34)
– Usual Care (UC) group (n = 34)
Eligibility Criteria

Inclusion Criteria
• Age 18 - 45
• Receiving ART for a minimum of 3 months
• Able to speak Telegu or English
• Signed informed consent

Exclusion Criteria
• CD4 cell count less than 100
• Not a participant of an earlier qualitative study.
Approved by:

- Ministry of Health, Government of India
- All India Institute of Medical Sciences (AIIMS)
- UCLA HSPC
Comprehensive Health Seeking and Coping Paradigm (Nyamathii, 1989)
Community Advisory Board

• 10 members including medical officers, nurses, WLAs, and Ashas
• Generated and Revised questions for the Semi-Structured Interview Guide (SSIG) for utilization in focus groups
ASHA-Life Intervention

Received six program-specific sessions:

1. HIV/AIDS & dealing with illness
2. Learning about ART and ways to overcome barriers
3. Parenting and maintaining healthy home environment
4. How to improve coping, reduce stigma and family care
5. Basics of nutrition and easy cooking tips
6. Benefits of engagement in life skill classes
7. NUTRITIONAL SUPPLEMENTS
Asha Life Model

Ashas played a key role in:

- Adherence monitoring
- Education on ART benefits and adherence
- Psychological support
- Bus tokens and accompanying women living with AIDS to hospital and clinics
- Worked closely with registered nurses
Usual Care Program

Received six program-specific sessions

1. HIV/AIDS & dealing with illness
2. Learning about ART and ways to overcome barriers
3. Parenting and maintaining healthy home environment
4. Q & A Sessions
5. Q & A Sessions
6. Q & A Sessions
7. NUTRITIONAL SUPPLEMENTS
Instruments

- **Socio-Demographic Information**: age, education, employment status, relationship status, number of children
- **Health History**: self-reported history of psychiatric diagnosis and treatment, health care access and utilization
- **CD4 Cell Count**: Flow Cytometry (Act Diff Coulter)
- **Adherence**: Pill Count
- **Depressive Symptoms**: The CES-D scale
Instruments

- **Body Composition Measurement**: weight, height, percent body fat, fat mass, lean mass (310e Bioimpedence analyzer), body mass index
- **Enacted Stigma**: Ten-item scale by Ekstrand and associates.
- **Help Getting ART**: Eight-item scale
- **Perceived ART Benefits**: Fifteen items using “yes/no” responses
- **Barriers to HIV medication adherence**: Eighteen-item scale
# Sample Characteristics

<table>
<thead>
<tr>
<th>Baseline Variable</th>
<th>AL Group</th>
<th>UC Group</th>
<th>Total</th>
<th>p valuea</th>
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<tr>
<td>(Range)</td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
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<tr>
<td>Age (20-45)</td>
<td>32.3</td>
<td>5.3</td>
<td>30.1</td>
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<td>CD4 Level (127-1071)</td>
<td>439.1</td>
<td>217.6</td>
<td>447.5</td>
<td>260.0</td>
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<tr>
<td>Months Taking ART (0-86.8)</td>
<td>25.6</td>
<td>20.5</td>
<td>19.1</td>
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<tr>
<td>Visits Past 3 Months (2-15)</td>
<td>7.7</td>
<td>3.5</td>
<td>7.4</td>
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<tr>
<td>Enacted Stigma (0-10)</td>
<td>6.4</td>
<td>3.6</td>
<td>7.9</td>
<td>2.5</td>
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<tr>
<td>Adherence to ART (22-88)</td>
<td>41.7</td>
<td>9.5</td>
<td>54.9</td>
<td>16.9</td>
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<td>Barriers to Adherence (0-27)</td>
<td>0.8</td>
<td>0.6</td>
<td>1.0</td>
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a. Chi-square or t-test for program differences
### Sample Characteristics

<table>
<thead>
<tr>
<th>Baseline Variable</th>
<th>AL Group</th>
<th>UC Group</th>
<th>Total</th>
<th>p value (^a)</th>
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<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
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<tr>
<td>Any Children</td>
<td>32</td>
<td>94.1</td>
<td>27</td>
<td>79.4</td>
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<tr>
<td>Married</td>
<td>15</td>
<td>44.1</td>
<td>20</td>
<td>58.8</td>
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<tr>
<td>At Least 4 Years of School</td>
<td>11</td>
<td>32.4</td>
<td>4</td>
<td>11.8</td>
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<tr>
<td>Hindu Religion</td>
<td>15</td>
<td>45.5</td>
<td>29</td>
<td>85.3</td>
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<tr>
<td>More than 47 Months since HIV diagnosis</td>
<td>22</td>
<td>66.7</td>
<td>11</td>
<td>32.4</td>
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<tr>
<td>Any Help Getting ART (^b)</td>
<td>16</td>
<td>47.1</td>
<td>9</td>
<td>26.5</td>
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<tr>
<td>Any Perceived ART Benefit</td>
<td>20</td>
<td>58.8</td>
<td>27</td>
<td>79.4</td>
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<tr>
<td>Depressed Mood (^c)</td>
<td>24</td>
<td>70.6</td>
<td>13</td>
<td>38.2</td>
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</table>

\(^a\) Chi-square or t-test for program differences

\(^b\) Help from family and friends

\(^c\) Based on a CES-D score of 16 or greater
In relation to having ASHA visit,

“If I fear stigma, then I lose my health, my children and husband, and my family will suffer. Why should I fear receiving support and change my life towards a healthier side? I am saying this from my heart and on behalf of all women living with AIDS”
Social Barriers to Adherence

- Difficulty paying for transportation
- Difficulty taking off time from work
- Lack of accompaniment

“On many occasions, when I am sick, no one accompanies me to the district hospital, even if I call someone to help me”

“I go alone to collect my medicines. By the time I come home, it is very late…”
Current HIV Delivery Model

- Need to travel 6 hours to the district hospitals
- PHCs only provided symptomatic care
- TB treatment and medicines are provided in PHS, but not ART
Social Barriers to Adherence

- Difficulty paying for transportation
- Lack of accompaniment
- Difficulty taking time from work.
Adherence to Antiretroviral Therapy (ART)
## Biologic Characteristics at Baseline

<table>
<thead>
<tr>
<th>Variable</th>
<th>AL&lt;sup&gt;a&lt;/sup&gt;</th>
<th></th>
<th>UC&lt;sup&gt;b&lt;/sup&gt;</th>
<th></th>
<th>Total Sample</th>
<th></th>
<th>p-value&lt;sup&gt;c&lt;/sup&gt;</th>
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<tbody>
<tr>
<td>Weight (kg)</td>
<td>46.2</td>
<td>7.9</td>
<td>43.8</td>
<td>7.1</td>
<td>45.0</td>
<td>5.6</td>
<td>0.20</td>
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<tr>
<td>Height (cm)</td>
<td>151.8</td>
<td>5.1</td>
<td>150.2</td>
<td>5.7</td>
<td>151.0</td>
<td>5.4</td>
<td>0.22</td>
</tr>
<tr>
<td>Body Mass Index</td>
<td>20.0</td>
<td>3.4</td>
<td>19.4</td>
<td>2.5</td>
<td>19.7</td>
<td>3.0</td>
<td>0.35</td>
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<tr>
<td>Lean Weight</td>
<td>33.4</td>
<td>5.2</td>
<td>31.8</td>
<td>5.4</td>
<td>32.6</td>
<td>5.3</td>
<td>0.23</td>
</tr>
<tr>
<td>Fat Weight</td>
<td>12.8</td>
<td>4.0</td>
<td>12.0</td>
<td>3.0</td>
<td>12.4</td>
<td>3.5</td>
<td>0.35</td>
</tr>
<tr>
<td>Percent Fat (%)</td>
<td>27.2</td>
<td>5.4</td>
<td>27.2</td>
<td>4.7</td>
<td>27.2</td>
<td>5.0</td>
<td>0.97</td>
</tr>
<tr>
<td>CD4 count</td>
<td>439.1</td>
<td>217.6</td>
<td>447.5</td>
<td>260.0</td>
<td>443.3</td>
<td>238.0</td>
<td>0.89</td>
</tr>
</tbody>
</table>

A: Asha-life  
B: Usual Care  
C: P-value Derived From One-way ANOVA
## Adjusted* Characteristics Over Time

| Variable                  | Mean AL Measures ± S.D. | Mean UC Measures ± S.D. | p-value  
|---------------------------|-------------------------|-------------------------|----------
|                           | Baseline  | 3 Month   | 6 Month   | Baseline  | 3 Month   | 6 Month   |          |
| Weight (kg)               | 46.2 ± 7.9 | 49.1 ± 7.9 | 51.4 ± 6.9 | 43.8 ± 7.1 | 41.9 ± 9.0 | 42.6 ± 8.3 | 0.0001   |
| Body Mass Index (kg/m²)   | 20.0 ± 3.4 | 21.3 ± 3.0 | 22.3 ± 3.0 | 19.4 ± 2.5 | 18.6 ± 3.6 | 18.8 ± 3.0 | 0.0001   |
| Lean Weight (kg)          | 33.4 ± 5.2 | 33.7 ± 6.2 | 36.1 ± 4.9 | 31.8 ± 5.4 | 31.4 ± 6.0 | 30.8 ± 6.1 | 0.0045   |
| Fat Weight (kg)           | 12.8 ± 4.0 | 14.7 ± 4.0 | 15.3 ± 3.3 | 12.0 ± 3.0 | 12.3 ± 2.8 | 11.1 ± 3.6 | 0.0001   |
| Percent Fat (%)           | 27.2 ± 5.4 | 29.6 ± 4.2 | 29.6 ± 4.2 | 27.2 ± 4.7 | 28.7 ± 5.1 | 26.0 ± 5.7 | 0.0009   |
| CD4 count\textsuperscript{d} | 439.1 ± 217.6 | 714.4 ± 293.3 | 447.5 ± 260.0 | 416.6 ± 234.9 |          |          | 0.0001   |
| ART adher (%)\textsuperscript{e} | 40.0 ± 11.0 | 99.0 ± 0.02 | 53.0 ± 0.2 |          | 67.0 ± 0.2 |          | 0.0001   |
Six-Month Follow-Up
BMR

1. No group differences were found in body composition measures at baseline

2. At six months, weight, BMR, percent fat, fat weight, and lean weight significantly higher in the AL group compared to the UC group (p < .05).

3. Using ANCOVA analyses to adjust for baseline values, all of the above measures were significantly higher in the AL group at six months (p < .01).
Conclusion

1. Ashas provide a unique service delivery model

2. High protein caloric supplementation combined with additional care provided by trained Ashas can result in increases in BMI and immune functioning.

3. As a package, the AL intervention was significant in impacting the outcomes assessed.
Asha Improving Health and Nutrition of Indian Women with AIDS and their Children

NIMH RO1 098729
2013-2017
Using a 2x2 factorial design, assess

1. Asha support alone for WLA, vs.
2. Asha support for WLA + nutrition training, vs.
3. Asha support for WLA + food, vs.
4. Asha support for WLA + training + food