Community Engagement in Research (CEnR) for Intimate Partner Violence and Child Maltreatment

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Learning Objectives

• Become familiar with key definitions of CEnR
• Become familiar with the rationale for conducting CEnR
• Understand core principles and values of CEnR
• Describe the 5’Ps of CEnR: Participate, Prepare, Predict, Preempt, and Prevent
• Identify how to use CEnR in Child Maltreatment and Intimate Partner Violence
Presentation Overview

1. Community Engagement in Research (CEnR)
   - True/False
   - Case 1
   - Definitions
   - Rational
   - Core Principles
   - Challenges
   - 5 P’s – Participate, Prepare, Predict, Preempt, and Prevent
   - Case 2
   - Case 3

2. Using CEnR in IPV
3. Using CEnR in Child Maltreatment
4. Case from the Healthier Wisconsin Partnership Program (HWPP)
5. Youth Violence Prevention Initiative
6. Discussion/Questions
True or False

Community Based Participatory Research (CBPR) is a research method by which research is done with communities.
True or False

To produce effective research with the community, the community needs to be defined by geography.

Ahmed, SM, Medical College of Wisconsin, 2010
True or False

Communities do not have reasons to distrust academics.
True or False

Bidirectional Dialogue” is a key process of CBPR / CER
True or False

Communities can be defined differently depending on the context.

Ahmed, SM, Medical College of Wisconsin, 2010
True or False

Community engagement can take many forms.

Ahmed, SM, Medical College of Wisconsin, 2010
True or False

Culture is not relevant in the Community Engaged Research process.

Ahmed, SM, Medical College of Wisconsin, 2010
True or False

Community is present, but academics are responsible for idea generation, decision making and responsibility.

Ahmed, SM, Medical College of Wisconsin, 2010
Case 1: Cardiovascular Disease vs. Diapers

Dr. Spring recently began working in a small rural area with a high concentration of significant cardiovascular disease risks and problems, and he has noted that there is no program or research in the town. He decided that it would be a good idea to develop a cardiovascular disease program for this county. He managed to approach some community leaders and was invited to come to a meeting to discuss his ideas. He went there full of enthusiasm and gave a small presentation on the need for cardiovascular risk reduction for the county. At the end, when he asked the audience if they had any questions, a woman raised her hand and asked, “Do you know where we can purchase inexpensive diapers for our children?”

A few days later, he was invited to go to the County Health Board. After he presented his idea, one key community leader in the county stated that his community did not need any such program. The gentleman, in a frustrated tone, explained that this community had many different programs over the years, and none of them worked. He also stated that the programs died with the departure of the key partnerships.

Case #1 Discussion

• How should Dr. Spring respond to the question raised by the audience member?

• What were the underlying challenges?

• What should Dr. Spring do following the objections he received from the community leader?

• What might Dr. Spring have done differently in presenting this issue to the community?

• Are there several things that should happen during the establishment of every community-academic partnership? Or is every partnership unique? Explain.

Defining Community

What we mean by “community” is dynamic and inclusive; there is no “one” definition of community.

Community need not be defined solely by geography. It can refer to a group that self-identifies by age, ethnicity, gender, sexual orientation, disability, illness or health condition.

It can refer to a common interest or cause, a sense of identification or shared emotional connection, shared values or norms, mutual influence, common interest, or commitment to meeting a shared need.

- A group of people linked by social ties who share common perspectives or interests, and may also share a geographic location (MacQueen et al)
- Communities are not homogeneous and seldom speak with a single voice.

What is in a Name?

- Community Engagement in Research (CEnR)
- Community Engagement in Research (CER) (?)
- Community Based Participatory Research (CBPR)
- Community Academic Partnership (CAP)
- Community Based Research (CBR) (Canada)
- Community Based Participatory Action Research (CBPAR)
- Dialogue Research
- Involved Research (UK)
- Community Engaged Research (CER)
- Community Engaged Scholarship
- Action Research (AR)
- Participatory Action Research (PAR)
- Empowerment Research

Ahmed, SM, Medical College of Wisconsin, *Community Engagement in Research (CEnR): A Framework for Education & Training* 2010
What is Community-Based Participatory Research (CBPR)?

“A collaborative approach to research that **equitably involves all** partners in the research process and recognizes the unique strengths that each brings.”

W.K. Kellogg Foundation
Community Engagement in Research (CEnR)

CEnR is a process of inclusive participation that supports mutual respect of values, strategies, and actions for authentic partnership of people affiliated with or self-identified by geographic proximity, special interest, or similar situations to address issues affecting the well-being of the community or focus.

Community Engagement in Research (CEnR)

- CEnR is a core element of any research effort involving communities. It requires academic members to become part of the community and community members to become part of the research team, thereby creating a unique working and learning environment before, during, and after the research.

Operating Principle

Community Engagement is a process that requires \textit{power sharing, maintenance of equity}, and flexibility in pursuing goals, methods, and time frames to fit the priorities, needs and capacity within the cultural context of communities. CER is often operationalized in the form of partnerships, collaboratives, and coalitions which do the following: \textit{help mobilize resources and influence systems}; change relationships among partners; and serve as \textit{catalysts for changing} policies, programs, and practices.

Why CEnR?

Community Demand → Can not be just guinea pig

Failure of “Traditional” research approaches:

98% of Americans receive their health care outside of academic medical centers

Funder Demand → Need to see impact

Demand for elimination health disparities → Potent alternative to “outside expert” driven research

Why CEnR?


The challenge of “Translational Research”

Active participation of the target population

Interest in the contextual factor (e.g. social, economical, cultural, environmental, etc.)

Enhance the relevance and use of the research data by all partners

Incorporation of local knowledge which overcome “community distrust of academic research

Provides resources (e.g. funds, training, job opportunities for communities

Israel et al, 1998)

Evolution of CBPR / CEnR

“Helicopter Research”


Tuskegee Experience 1932-1972
Kurt Lewin
Canada Netherlands

• Paul Friere
• Latin American Asia, Africa
• Fals-Borda

CCPH: Community-Campus Partnerships for Health
NAPCRG: North American Primary Care Research Group
AHRQ: Agency for Healthcare Research & Quality
NIH STEP: Staff Training in Extramural Programs

NIH: National Institute of Health
CDC: Center for Disease Control & Prevention
PRC: Prevention Research Center
COPR: NIH’s Director’s Council of Public Representatives

Syed M. Ahmed; Evolution of CBPR, June 6, 2007
Federal Advisory Committee
Consists of 21 members of the public who provide input and feedback from the public’s perspective on emerging health issues and research priorities as identified by the COPR and/or the NIH Director
A diverse group with a wide range of backgrounds and perspectives
Purpose of COPR’s Focus on Community Engagement

Identify ways to encourage researchers to involve the public in research with an emphasis on community engagement.

COPR Methods:

- Role of the public work group
- Review 650 peer-reviewed articles
- Community & academic experts
- Presentation to & acceptance by the NIH Director
- Write up & publication
Core Principles of Community Engagement in Research (CEnR)

- Defined Community & Program Scope
- Strong Community-Academic Partnership
- Equitable Power and Responsibility
- Capacity Building
- Effective Dissemination Plan

Stages of Partnership Development

- Establish and build relationships
- Assess needs and resources
- Develop common goals
- Develop and implement programs
- Provide continuous feedback
- Check in on progress
- Maintain and expand progress
Challenges - Methodological

- Partnership between the researcher and the researched
- Issues of generalizability
- Decision about methods/data collection and analyses
- Knowledge differential between the research and the community
- Not a method, but “a process”
Challenges - Institutional

- “Novel” idea
- Lack of leadership
- Lack of faculty with CBPR / CEnR expertise
- Lack of infrastructure support
- Faculty development issues
- IRB issues
- Missing “boat” vs. Jumping on “bandwagon”

Challenges - National

- Slow evolution of CBPR / CEnR
- Resistance to new concepts
- Questions of legitimacy as a research paradigm
- Questions of lack of data on effectiveness of CBPR / CEnR
- Lack of leadership
- Lack of funding

Challenges - Community

- Lack of trust of academia
- Not Same missions / goals / priorities
- Lack of understanding of CBPR / CEnR
- Lack of understanding of roles / responsibilities
- Lack of skills in developing partnerships with academics
- Funding issues
- Who owns data?
- Who disseminates?
- Considerable investment of time and energy to build and sustain relationship
- Location of “power” in the partnership

Challenges - Individual

- Lack of education/training
- Lack of role model
- Skepticism
- Promotion & tenure issues
- Lack of support: departmental & institutional
- Considerable investment of time and energy
Strategies for 5 “Ps”: Prepare, Predict, Preempt, Prevent, and Participate

**Prepare**
- Learn about community’s history and past experiences
- Learn about socio-economic & cultural background
- Use strategic planning when appropriate

**Predict**
- Predict both success and challenges
- Have plan to address challenges

**Preempt**
- Learn potential challenges
- Use plan to address challenges
- Do not ignore major or minor issues

**Prevent**
- Use plan to prevent negative impact on the program
- Be proactive in taking steps to prevent untoward outcomes
- Do not let critical issues go unaddressed

**Participate**
- Use bidirectional communication
- Be flexible and dynamic
- Use reciprocal learning
- Be transparent

Three major organizations in Dayton, Ohio came together to address issues of the underserved. They agreed that three institutions among them with multiple other organizations could bring enough strength to go for a major national grant which would address the healthcare need of uninsured populations in Dayton. The key persons leading the project had significant knowledge in developing community-academic partnerships. After it was announced that the Dayton community had received the grant, beating a great odd; the most significant change came from inside. One of the key organizations, who also served as the sponsoring agent for this grant decided that they did not want to be a partner on this project. They wondered about any future potential malpractice related to patient care and wanted to get off this partnership.
Case #2 Discussion

- What are the ethical issues in this situation?

- What will the implications be of the sponsoring agent leaving the partnership?

- What was missed at the initiation of the partnership?

- What is the best way to deal with this situation?
Case 3: Use of a Strategic Plan

Like many other medical schools, an urban Midwest medical school was facing challenges in establishing effective partnerships with neighboring communities. It also did not have significant effective partnerships with the communities around it. This medical school had no history of working with churches. Communities in similar settings often either have no opinion or negative opinion of medical institutions. Given this context, I was asked to develop a program with churches, since I had developed similar programs in a different city. This time, I followed a somewhat longer and more deliberate process.
Case #3 Discussion

• Important to consider operating structure of the organization

• Respect the organization’s decision-making process

• Buy-in from pastors has been crucial

• Negative perceptions of an institution are usually based on real events from the past
Intimate Partner Violence (IPV)

Of 2555 articles in PubMed on Intimate Partner Violence since 1999, 13 were identified to have used community engagement in research approach (CEnR)

*This was determined through search terms of the 2555 articles identified*
Southwest Detroit Partnership to Prevent Intimate Violence Against Latina Women

- **Problem:** Intimate Partner Violence Against US Latina Women
- **Historical Context:** 1991-1992 survey found 40% of 176 Latino women aged 18-65 in Southwest Detroit reported experiencing incidents of physical and emotional abuse
- **Approach to solve problem:** Community-Based Participatory Research – A partnership Approach
- **Partnership:** Detroit Community-Academic Urban Research Center, 6 CBOs, Detroit Health Department and UM-School of Public Health
- **Methods:** Individual interviews, group interviews, field notes, content analysis identifying major themes

Child Maltreatment

Of 2106 articles in PubMed on Child Maltreatment since 1999, 5 were identified to have used community engagement in research approach (CEnR)*

*This was determined through search terms of the 2106 articles identified
Community Level Prevention of Child Maltreatment

- Problem: Child maltreatment in Durham, North Carolina
- Historical Context: 2000-2001 population rate of substantiated maltreatment of children under 6 was 28 per 1000, substantially higher than the state and national rate
- Approach to solve problem: Community co-ownership approach – interventions at the individual, family, community and policy level
- Partnership: private business, philanthropy, public agencies and government leaders (police department, public schools, city manager’s office, health department, mental health center, juvenile court, county commissioner)

Healthier Wisconsin Partnership Program (HWPP)

Intimate Partner Violence Projects

• Domestic Violence Screening in South Central Wisconsin
• Healthcare Can Change From Within: A Sustainable Model for Intimate Partner Violence
• Community Readiness for LGBT Intimate Partner Violence Support Services
• Milwaukee County Health Care Intimate Partner Violence Consortium
• Project Respect
Youth Violence Prevention Initiative (VPI)

• 3 programmatic priorities:
  1. Implement violence prevention programs for youth ages 0-11
  2. Develop leadership capacity to prevent violence among youth ages 12-17
  3. Build and strengthen community capacity and resources to prevent violence

• 2 partnership teams
  1. Holton Youth and Family Center Collaborative (HYFCC)
  2. UNCOM Violence Prevention Initiative

• Resource Repository
  1. VPI Project and Partners
  2. Local and Statewide Violence Related Reports and Programs
  3. Evidence Based Best Practices in Violence Prevention
  4. Community Planning and Development Models
  5. Violence-Related Research Literature

• VPI-Research and Evaluation Team (VPIRET)
  Evaluation of Community Partnership Team programs, research and capacity building/training/ workshops on violence-related topics and evaluation.

“When facing a difficult task, act as if it is impossible to fall. When going after Moby Dick, bring along the tartar sauce.”

Anon
Thank You

Any Questions?

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IPV References

Child Maltreatment References

CEnR References


• Ahmed SM, Beck B, Maurana CM, Newton G: Overcoming Barriers to Effective Community-Based Participatory Research in U.S. Medical Schools. Education for Health: Change in Learning and Practice, 2004; 17(2): 141-151.


