Community-Driven Research: Principles, Models, Community Impact

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Foundations of Trust:
Connecting our Community to Research
Hartford Health Care and
Office of Human Research Protection
Broad Questions

- If solutions to health inequities/experienced by Latinos and other diverse communities were community-driven, what would they look like?
- Is teaching a person to fish enough?
Objectives

After this presentation, participants will be able to:

1. Identify examples of ethical and effective community engagement in research.
2. Describe elements of an equitable community-academic-clinical partnership.
3. Identify key principles of community-based participatory research (CBPR).
4. Describe community impact of a CBPR project.
Themes

- Community-based participatory research (CBPR)
- Community context
- Community-based organization
- Cultural competence; organizational cultural competence; structural competence
- Equitable partnership
- Community assessment; Community-informed interventions
- Community Health Workers (CHWs)
- Social determinants of health
- System change
Hispanic Health Council (HHC)

- Mission: To improve the health and social well being of Latinos and other diverse communities
- Community-based organization
- Incorporated 1978, in response to identified need for organization focused specifically on Latino health
- Founded by medical anthropologists and community activists/leaders

HHC’s Core Strategies
- Translational/community-based participatory research
- Evidence-based direct services
- Provider Training
- Policy advocacy
FACTORS THAT IMPACT HEALTH

Socioeconomic, Cultural & Political Environment

Social & Physical Environment

Stress – Could be 40%

“Structural Competence”

Organizational Cultural Competence

Individual Lifestyle Factors

Patient’s Culture

Provider Cultural Competence

Biological Features (Age & Genetics)

Quality, Patient-Centered Healthcare

Health Care 10-20%

Adapted From Alameda County Department of Public Health
Approaches to Addressing Health Inequities in Experienced by Latinos

- Within Health Care: Capacitation of Clinical Health Care Teams: Training of Providers in Cross-Cultural & Diversity Inclusiveness and Health Equity
- Expansion of Health Care/Clinical Health Care Teams: Evidence-Based Community Health Worker Service Models
- Culturally Competent Community Education
- Community-Designed Strategies to Address Social Determinants of Health
Capacitation of Clinical Health Care Teams

- Training of Providers in Cross-Cultural & Diversity Inclusiveness, Health Equity and Structural Competence
- In response to 2003 landmark IOM report “Unequal Treatment” - recommended cultural competence for health care providers, addressing knowledge, attitudes and behavior; and more recent research;
- 2014 National Healthcare Quality and Disparities Report states that problem persists
- Over 3,000 trained: participatory, addresses stereotyping and blaming the victim, teaches cultural brokering...
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Strategy: Expansion of Clinical Health Care Teams: Evidence-Based, Culturally Competent Community Health Worker (CHW) Service Models
Why the term Community Health Worker (CHW)?

Umbrella term that unifies many diverse functions as part of the same workforce:

- Community Health Advocate
- Peer Counselor
- Peer Coach
- Patient Navigator
- Care Coordinator
- Etc.

- Promotora de Salud
- Peer Leader
- Outreach Educator
- Outreach Worker
- Case Manager
- Health Educator
- Etc.

Massachusetts identified 66 terms...
CT Definition of CHWs
(approved by the State Innovation Model CHW Design Group, 10/2016)

“A Community Health Worker (CHW) is a front line public health worker who is a trusted member of, and/or has a unique understanding of the experience, language, culture, and socioeconomic needs of the community served. A CHW serves as a liaison/intermediary between individuals, communities and health and social services to facilitate access to care, improve the quality and cultural responsiveness of service delivery, and address social determinants of health.

CHWs build individual and community capacity by increasing health knowledge and self-sufficiency through a range of culturally appropriate services such as: outreach and engagement; education, coaching, and informal counseling; social support; advocacy; care coordination; basic screenings and assessments; and research and evaluation.”
HHC: Community-Based Hub of CHW Services

- Prenatal Case Management
- Parenting Education and Support
- Cancer Early Detection
- Cancer Survivorship Support
- Substance Abuse Case Management
- HIV Medical Case Management and Behavioral Health Services
- SNAP Outreach
- **Breastfeeding Peer Counseling**
- **Diabetes Peer Counseling**
- Supported Employment for Persons with Serious Mental Illness
- Domestic Violence Education
- Youth Development: Academic and Family Support
Breastfeeding Promotion:
Breastfeeding Heritage and Pride Peer Counseling Program

- Program model designed through community focus groups
- Health promotion/obesity prevention – education, support, modeling – specific health practice
- Peer counselors conduct:
  - Home and clinic-based prenatal visits
  - Post partum hospital rounds and post partum home visits
  - Education in WIC office, with clients of prenatal home visiting programs
- Partnership with prenatal and post partum clinical teams
- Community-based service, deployed to prenatal and post partum clinical and community sites, providing a citywide system of breastfeeding support
Breastfeeding Promotion:  
Breastfeeding Heritage and Pride Peer Counseling Program

- Original partnership between Hispanic Health Council and Hartford Hospital
- Evaluated through RCT through partnership with UConn/Yale;
- Strong evidence for improved outcomes
- Replicated at Yale New Haven WIC Program
- Expanded to Saint Francis Hospital through Kellogg grant –
- Potential for national replication
- Mobile Research: LATCH: Peer counseling plus texting study
- ONGOING PROGRAM


Chronic Disease Management:

Diabetes among Latinos Best Practices Trial

- Community-based intervention, Randomized controlled trial
- Partnership between UConn/Yale, HHC, H.Hosp.
- Funded by the CT NIH EXPORT Center of Excellence for Eliminating Health Disparities among Latinos, PI Dr. R. Pérez-Escamilla
- Intervention design informed by community assessment: 17 home visits to low-income Latino patient with diabetes
  - Nutrition education; hands-on activities to encourage behavior change:
    - Walks in park with pedometer
    - Label-reading at supermarket
  - Observation of glucose monitoring
  - Care coordination – health care and SDOH
  - Identification of problems with diabetes management, gaps in clinical care
- Weekly meetings and regular phone contact with clinical health care team at Hartford Hospital’s Brownstone Ambulatory Health Care Clinic
Chronic Disease Management:
Diabetes among Latinos Best Practices Trial

Results:
- HbA1C level reduction at 12 months:
  - 1 point in the intervention (PC) group
  - 0.4 point in the control (no PC) group
  - Impact sustained through the six-month post-intervention period (18 months)
  - Follow-up RCT: community health educator delivery of stress management training to Latinos with diabetes, results recently published

- STUDY – ENDED WHEN STUDY ENDED


Evidence-Based, Culturally Competent Community Health Worker (CHW) Service Models

- Often developed based on community-based assessment and formative research
- Conducted in partnership
- Empowered, hands-on roles
- Rigorous training and supervision
- Culturally relevant
- Integrated into clinical health care teams and community settings
- Clear delineation of function/tasks – CHW: Clinician
- Reinforce clinical guidance, address social determinants of health, create interface between clinical and community settings
- Evaluated - three randomized trials completed
  - One on health promotion (breastfeeding)
  - Two on chronic disease management (diabetes)
- Two Symposia, participation in development of CHW design in CT health care reform

*Dr. R. Pérez-Escamilla
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Adapted From Alameda County Department of Public Health
Strategy: Culturally Competent Community Education

- Social marketing
- *Fotonovelas*
- Participatory education sessions
  - Puppet Shows
  - Jeopardy Games
  - Hands-on Educational Sessions
HHC SNAP-Ed Program

Launched with community nutrition assessment
Partnership UConn/HHC

Nutrition Education: major emphasis on obesity prevention, promotion of fruit & vegetable consumption and physical activity:

- Six Puppet Shows: Pre-K through 3rd Grade – one on diabetes prevention
- Four jeopardy games
- Interactive presentations, taste-testing
- Linkage to policy/systems/environment initiatives that enable access to quality food.
Social Marketing Campaigns

Developed and evaluated by HHC in partnership with UConn
FOTONOVELAS

- A culturally relevant educational tool for Latinos
- Appeal to audiences with limited literacy, and limited access to full-length books
Fotonovelas: Translated by HHC into a health education tool

Fotonovelas on the SNAP Program have been distributed nationally to DSS offices

Current fotonovela project:

- American Heart Association Partnership
- “Life’s Simple 7” theme
- Developed with formative research – series of community focus groups
- Pre/post-test evaluation measuring change in knowledge and self-efficacy
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Strategy: Community-Designed Strategies to Address Social Determinants of Health

Hartford Mobile Market
An Example of Community-Based Participatory Research -

Questions and solutions generated in and by the community...
Structural Competency

“The trained ability to discern how a host of issues defined clinically as symptoms, attitudes, or diseases (e.g., depression, hypertension, obesity, smoking, medication “non-compliance,” trauma, psychosis) also represent the downstream implications of a number of upstream decisions about such matters as health care and food delivery systems, zoning laws, urban and rural infrastructures, medicalization, or even about the very definitions of illness and health.”

(Metzl, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4269606/2014)
Need for Increased Access to Fruits and Vegetables in Hartford

- The USDA considers a neighborhood a food desert if at least a fifth of the residents live in poverty and a third live more than a mile from a supermarket in urban areas, or more than 10 miles in rural areas, where residents are more likely to have cars.

- Large food retailers opened 14 new supermarkets across Connecticut from the end of 2011 to the beginning of this year, but none in areas deemed by the federal government to need them the most, according to an analysis by The Associated Press.

- Hartford had 13 full-size supermarkets in 1968,
  - has only one now – one the West Hartford line, along with a Walmart located near the supermarket;
  - West Hartford has half the population of Hartford, has 7 supermarkets – implications for accessibility and price competition

(JHCPU, Nov. 2011, 22.4)
Key Principles of CBPR

- 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 (involves a long-term process and commitment)
- Addresses health from both positive and ecological perspectives
- Disseminates findings and knowledge gained to all partners
- While principles are a useful guide, they should not be imposed upon a project or partnership, but allowed to continually evolve to reflect changes in the research context, purpose and participants. The process of developing principles and making decisions about the partnership's characteristics is essential to building the infrastructure of the partnership.

In 2009, CEHDL’s Community Core conducted a series of community focus groups with low-income Puerto Rican women in Connecticut.

The purpose of the focus groups was to document the social determinants of stress, from their perspective.

Among the results, participants identified food insecurity (including running out of food and limited access to healthy food) as a stressor that impacts maternal health.

(JHCPU, Nov. 2011, 22.4)
Community Calls for Access to Healthy Food

- Focus groups were followed by a community dialogue on social determinants of maternal health
  - Community members
  - Community leaders

- Community members were presented with stressors identified during focus groups and asked for solutions

- Community leaders responded by committing work towards achieving the solutions

- Results from the dialogue included the following solutions to food insecurity recommended by community members:
  - Establish a community garden
  - Create a mechanism to maximize the benefits of social services including WIC and SNAP
Formative Research on fruit and vegetable access:

- Conducted after focus groups and dialogue
- By a multi-disciplinary team of CEHDL's Community Core
- To develop an innovative, feasible and sustainable method of increasing access to fruits and vegetables in Hartford's south end

The formative process included:

- A series of brainstorming sessions among team members
- A focus group and individual conversations with HHC staff
- A series of focus groups and interviews with community members
- Conversations with key food security leaders from a variety of government and private organizations at the city and state levels
- Extensive review of literature
- Field research to determine locations where increased access to fruits and vegetables are most needed
Prior CBPR Formative Research

CEHDL Focus Groups Identified Food Insecurity Stressor

CEHDL Community Dialogue Identified Some Solutions

Community-Based Participatory Research - Formative Research on Increasing Access to Fruits and Vegetables Leading to Hartford Mobile Market Concept

Conversations with leaders representing SNAP, WIC, farmers markets, Hartford Food System, nutrition education, the regional food bank, local health department, advocacy

Establishment of...

Community Advisory Board

CEHDL Steering Committee/Trans-Disciplinary Team

HHC Staff, Key Informants

Target Community Members

Key considerations:
- Location and schedule
- Produce source, selection, local vs. non-local, in-season vs. not in-season
- Sales volume and price
- EBT – SNAP, FMP, WIC vouchers
- Other

Community Calls for Access to Healthy Food – Community Designs Hartford Mobile Market

ONLY ONE FULL-SCALE SUPERMARKET IN HARTFORD
Hartford Mobile Market

- Operated by Hartford Food System
- Year-round, local and non-local produce
- Use of WIC, SNAP, FM Coupons, Cash
- 14 current sites, in locations identified by community that lack access to high quality, affordable produce
- Hartford Hospital major partner- planning Food As Medicine Project “prescription of fruits and vegetables” for low-income patients with diabetes *(HHC, Yale SPH, HFS, HHosp.)*
- Nutrition Education and Texting – Assessing added value to SNAP-Ed of linkage to HMM through texting and provision of coupons to HMM *(HHC, YSPH)*
Elements of an Authentic Partnership - Principles

1. The partnership forms to serve a specific purpose and may take on new goals over time.

2. The partnership agrees upon mission, values, goals, measurable outcomes and processes for accountability.

3. The relationship between partners in the partnership is characterized by mutual trust, respect, genuineness, and commitment.

4. The partnership builds upon identified strengths and assets, but also works to address needs and increase capacity of all partners.

5. The partnership balances power among partners and enables resources among partners to be shared.

6. Partners make clear and open communication an ongoing priority in the partnership by striving to understand each other's needs and self-interests, and developing a common language.

Elements of an Authentic Partnership - Principles

7. Principles and processes for the partnership are established with the input and agreement of all partners, especially for decision-making and conflict resolution.

8. There is feedback among all stakeholders in the partnership, with the goal of continuously improving the Partnership and its outcomes.

9. Partners share the benefits of the partnership's accomplishments.

10. Partnerships can dissolve, and when they do, need to plan a process for closure.

11. Partnerships consider the nature of the environment within which they exist as a principle of their design, evaluation, and sustainability.

12. The partnership values multiple kinds of knowledge and life experiences.

Conclusions

- Health inequity solutions need to be culturally competent and community-driven.
  
  - Thus, need for regular community engagement.
  
  - Thus, need for major role played by community-based organizations.

- Teaching to fish is not enough!
  
  Equity in income, education, environment, health care are essential to addressing health inequities. These require major policy/systemic change.
¡MUCHAS GRACIAS!

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