Translational Research at the Community Level: New Perspectives, New Questions, New Solutions

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National Conference on Engaging Patients, Families and Communities in all Phases of Translational Research to Improve Health

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Themes

- Benefits to basing health disparities research within communities and generating research questions at the community level.

- Community-based infrastructure needed for community-based health disparities research

- Expertise of community-based health disparities researchers and research organizations needed by faculty and students in academic settings
Translational Research at the Community Level: New Perspectives, New Questions, New Solutions

Case Example: Hispanic Health Council

- Community-Based Research Organization
- Early Research/Policy Impact
- Research in Partnership
- Research Infrastructure Over Time
- Implications for Infrastructure/Resource Needs for Community-Based Health Disparity Research
Case Example: Hispanic Health Council

- Community-Based Organization in Hartford, CT
- Mission: To improve the health and social well-being of Latinos and other diverse communities
- Founded in 1978, works statewide, nationally recognized

Core Strategies

- Community based participatory research
- Evidence based direct services
- Policy advocacy
- Provider Training
HHC Case Study Context, Founding Story

Context:
- 1970s, growing numbers of Latinos (mostly Puerto Ricans) in Hartford
- Service system, including health service system not developing according to cultural and other needs of Latinos
- Development of some Latino leadership, infrastructure, focused mostly on housing and jobs

Founding story
- Death of eight-month old Rosa Maria Rivera (1973), due to language barrier in two Emergency Departments catalyzes formation of the “Puerto Rican Health Task Force”, established by community activists, university faculty and students
- Grant received from NIMH to study PR health adaptations, combined with grant received from local foundation (HFPG) to fund administration allowed for establishment of new organization focusing on Hispanic health
- HHC incorporated in 1978
- Original vision: use research to identify needed system and policy changes, advocate for changes
HHC Early Research Work - Community-based research leading to system/policy change

- NIMH grant received to study PR health beliefs and how the community accessed health care – late 1970s
  
  - Findings – of 153 heads of household interviewed, 51.6% reported themselves to have been sterilized
  
  - Intensive follow-up interviews conducted, along with analysis of historical, socio-economic and cultural factors linked to this
  
  - Among key issues uncovered:
    - Informed consent form provided only in English
    - Lack of thorough counseling about the procedure
    - Thus, lack of awareness of permanence of procedure
  
  - Impact:
    - Advocacy for policy changes related to informed consent process
    - Future HHC programs incorporated education about fertility control into program design
HHC Early Work - Community-based research leading to system/policy change

**HIV/AIDS/Substance Abuse Work – beginning in 1980’s**

- Pioneered community education on taboo (HIV) subject
- Conducted community assessment on attitudes toward syringe exchange (SE), used results to advocate for SE funding
  - Evaluated SE, used results to advocate for continued funding
- Series of studies on cultural approaches to substance abuse treatment, synergistic relationship between substance abuse, AIDS and violence and related topics (Singer, NIDA/SAMHSA/CSAT)

**Hunger and Food Security Work – starting in late 1980’s**

- Conducted Hartford Community Childhood Hunger Identification Project, part of national study, first to document “hunger”
- Results: high levels of food insecurity
- Policy report released at press conference
  - Establishment of one of the country’s first Food Policy Advisory Commissions (to Mayor’s Office and City Council) – still exists
  - Continued hunger/food security work at HHC
HHC Early Work – Health/Health-related education and support services

- Beginning in 1980s, HHC adds service provision as a core strategies
  - HHC notes gaps in services and existing services that are ineffective with Latinos and other targeted populations.
  - HHC uniquely positioned to fill gaps, sees it as its responsibility

- Federal demonstration grant secured in partnership with CT Dept. of Public Health in response to high infant mortality rates in Hartford neighborhoods
  - HHC’s first Community Health Worker (CHW) service program developed
  - *Comadrona* Program continues today as part of citywide MCH service system and statewide Health Start Program
  - Evaluated as part of statewide Healthy Start program, found to be effective at improving birth outcomes, and cost effective

HHC Early Work – Provider Training

- Conducted since HHC’s inception
- Conducted with health and human service providers, also with police and others that interact with community members
- Combination training/advocacy
Community-Based Research Conducted in Partnership
Case Example:

*Dr. Rafael Pérez-Escamilla
Community Nutrition Assessment of Latino Children

Main Results:
- Suboptimal infant feeding practices
- Very low intake of fresh fruits and vegetables
- Frequent TV viewing
- One out of every six preschoolers were obese
- Very high levels of food insecurity
  - One out of every five preschoolers experienced episodic hunger

Impact:
- Guided development of Hispanic Family Nutrition Program (FSNE/SNAP-Ed)
- Guided development of follow-up research
- Public event held to disseminate results, results used by advocates, community agencies and academics to inform their work
HHC in Partnership

- Partnership initiated by UConn, based on FSNE/SNAP-Ed funding
- Shared budget, leadership, planning, data, dissemination of results
HHC SNAP-Ed Program

Nutrition Education Puppet Shows: Pre-K through 3rd Grade
HHC’s SNAP Education Program (SNAP-ED: PANA: Programa Para Aprender Sobre Nutrición y Alimentación)

- Provides a comprehensive, culturally appropriate approach to nutrition education, including:
  - Six puppet shows for pre-k to 3rd grade
  - Four jeopardy games for older children and adults
  - Hands-on presentations
  - Social marketing campaigns developed, disseminated, evaluated
  - Bilingual nutrition education materials developed

- Operates in seven Connecticut cities, including:
  - Four of the five most populous cities
  - Six of the eight with the highest Latino populations
  - The six cities with critical levels of poverty (50% above the state average)
HHC’s SNAP Education Program (SNAP-ED: PANA: Programa Para Aprender Sobre Nutrición y Alimentación)

HHC SNAP-ED Program Evaluation (puppet show component):

- Teacher satisfaction documented after each puppet show, consistently very high
- Anecdotal evidence regularly documented by teachers indicating that children’s eating behavior changes after viewing puppet shows – including increased fruit and vegetable consumption.
- Anecdotal evidence reported by parents that information sent home impacts family dietary habits
- HHC is collecting pre and post data on adult increased knowledge
- HHC/Yale (Pérez-Escamilla) seeking support for full evaluation of program impact
- Program featured in HHC video submission to “Let’s Move Faith & Community-Based Video Competition”
  - Honorable Mention received
  - HHC invited to the White House by First Lady Michelle Obama
HHC in Partnership: HHC-UConn Starting 1995
SNAP-Ed Program

Formative Research

Hispanic FNP

Marketing Campaigns

Breastfeeding Promotion and Support

PANA Nutrition Education Program

Culturally Competent Nutrition Education Materials

Research & Evaluation

New Research Questions Generated

Policy Impact

Translational Research at the Community Level: New Perspectives, New Questions, New Solutions
Evidence-Based Community Health Worker (CHW) Service Models

- Developed based on assessment and formative research
- Empowered, hands-on roles
- Rigorous training and supervision
- Culturally relevant
- Integrated into clinical health care teams
- Clear delineation of function/tasks - CHW: Clinician
- Evaluated
  - two randomized trials completed, one underway
    - One on health promotion (breastfeeding)
    - Two on chronic disease management (diabetes)
Community-Based Research Conducted in Partnership
Case Example: HHC, UConn, Hartford Hospital

*Dr. Rafael Pérez-Escamilla
Continued Partnership – HHC, UConn, Hartford Hospital

CHW Model for Breastfeeding Promotion: Breastfeeding Heritage and Pride Program

Program developed from formative/assessment research conducted by HHC:

- Qualitative interviews, focus groups, community surveys

Main research findings:
- Misinformation and lack of information
- Lack of role models and support figures
- Shame and embarrassment regarding breastfeeding

Program Goal
- To increase the rates of breastfeeding initiation and duration of breastfeeding among low-income women who give birth at Hartford Hospital

Client services
- Prenatal and post partum, home, clinic and hospital visits, post partum hospital rounds
- Telephone outreach and support
- Pump lending
Continued Partnership – HHC, UConn, Hartford Hospital
CHW Health Promotion Model: Breastfeeding: Heritage and Pride Program

Evaluation

- Initiated by HHC due to policy discussions that indicated lack of confidence in peer counselor capacity
  - HHC invited Dr. Pérez-Escamilla into discussions
  - HHC and Dr. Pérez-Escamilla decided research was needed to evaluate program model
- Randomized Controlled Trial conducted by HHC, UConn and Hartford Hospital
- Funded by CDC through the Association of Teachers of Preventive Medicine, CT Family Nutrition (SNAP-Ed) Program, and Hartford Hospital
- Objective: to assess the effectiveness of an existing breastfeeding peer counseling program serving a predominantly low-income Latina population in Hartford, CT

Evaluation Results

- BHP Effective – significant differences in initiation and duration
- BHP Cost-effective - healthier children, savings to society

Recommendations

- Expansion of peer counseling efforts
- Continued research
Impact of Evaluation

- Included in CDC Guide to Breastfeeding Interventions (2005) and IOM report “Accelerating Progress in Obesity Prevention: Solving the Weight of the Nation” (2012)
- Continued breastfeeding peer counseling and related research
- Research influences decision of federal government to fund peer counseling through the WIC Program, HHC one recipient of those funds in CT
- HHC program expanded and replicated

Continued Research by HHC/UConn-Yale, Hartford Hospital Research Team

- Use of peer counselors to support Exclusive Breastfeeding (funded by CDC)
- Use of peer counselors to support breastfeeding among obese women (funded by Donaghue Fndtn.)
- Eddy – Understanding effect of BESTOW peer counselor intervention through analysis of video-taped feeding sessions (funded by CDC)
- Case-control needs assessment (N=201)
- Self-reported diabetes without complications
- Latino women between 35 – 60 years old

Results:
- High level of health problems/ inadequate health care access - subspecialty care
- High level of food insecurity
- Low level of basic nutrition knowledge and food label utilization
- Low understanding and low self-efficacy levels regarding overall diabetes care
- Low levels of social support – suggested high levels of depression
- Clinical symptoms of inadequate diabetes management
- Disseminated through press event calling for peer counseling
Continued Partnership – HHC, UConn/Yale, Hartford Hospital

Connecticut EXPORT Center for Eliminating Health Disparities among Latinos

Three Institutional Partners:
- UConn/Yale (PI, Director), Rafael Pérez-Escamilla
- The Hispanic Health Council (co-PI, Deputy Director, Grace Damio)
- Hartford Hospital (co-PI, Laurine Bow)

Funder: NIH-NCMHD
Funding Level: $8.2 million
Period: 2005-2011
HHC budget – 45%
CEHDL Partnership

Adaptation of CHW Health Promotion Model to Chronic Disease Management: Diabetes among Latinos Best Practices Trial (DIALBEST)

- Randomized longitudinal trial examining the impact of home-based peer counseling on behavioral, metabolic, and health outcomes among inner-city Latino(a)s with type 2 diabetes
- 17 home visits in 12 months; intervention includes education and care coordination/advocacy
- Peer counselors met with clinical team weekly for case conferencing
- Extensive data collection, including blood draws, at baseline, 3, 6, 9, 12 mo. & 6 mo. post intervention

HHC Roles:
- Co-Investigator, Coordinator, Peer Counselors, Interviewer/Phlebotomist
- Data collection, cleaning, management
- Peer counseling services
- Peer counseling manual development
- Participation in leadership/planning team
- Participation in evaluation, authorship, presentations
CHW Models: Diabetes Peer Counseling Intervention Study (DIALBEST)

Results/Impact:

- 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) (Diabetes Care, 8/14)

- Gaps in health care identified by peer counselors, resulting in training of medical residents:
  - Case presentations by peer counselors
  - Cross cultural training by HHC program

- Follow-up study underway: impact on glycemic control among Latinos with diabetes of stress reduction training conducted by community health educator
  - Implications for inclusion of CHWs in health care reform

- Qualitative sub-study conducted on complex data collection by community staff
CEHDL Partnership

Other HHC CEHDL Role: Education and Training Core – Cultural Competence Training

- **Enhanced existing HHC curriculum for:**
  - Training medical residents
  - Health equity training at local health departments
  - Development and delivery of undergraduate semester-long course
  - Training community health workers, clinicians and researchers involved with CEHDL
  - Delivery of a series of grand rounds presentations at Hartford Hospital

- **Current Status:**
  - HHC fee-for-service contracts with (among others):
    - UConn Health Center Graduate Medical Education Program
    - Saint Francis Hospital and Medical Center
    - Connecticut Hospital Association
    - CT Department of Education
  - Beginning of process to evaluate beyond self-report
Other HHC CEHDL Role: Leadership of the Community Core

Community Core Projects:

- Community newsletter on health disparity topics targeting Community Health Workers
- Evaluation of HHC’s annual health fair, new model developed based on evaluation results
- Youth development pilot project – health disparities focus
- Annual community focus groups on health disparity topics
- Annual facilitated community dialogues on health on health disparity topics, involving responses from community leaders
- Formative research on a community informed strategy to increase fruit and vegetable access
CEHDL Partnership: Community Core

Hartford Mobile Market

An Example of Community-Based Participatory Research

Questions and solutions generated in and by the community...
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 who live in Hartford's south end
- A series of focus groups and interviews with community members
- Conversations with key leaders in the area of food security 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

CEHDL

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

Community Advisory Board

CEHDL Steering Committee/Trans-
Disciplinary Team

HHC Staff,
Key Informants

Target Community
Members

Establishment of...

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

Phase 1: Community Focus Groups
Phase 2: Community Focus Groups/Individual Interviews

Hartford Mobile Market

Translational Research at the Community Level:
New Perspectives, New Questions, New Solutions

CEHDL Partnership: Community Core
Hartford Mobile Market

- Concept: seamless source of fresh produce that maximizes access and responds to expressed community needs and wants, documented through our extensive formative research we conducted, by:
  - operating year-round
  - North and south ends – HHC conducted focus groups in north end to inform operations from north-end perspective
  - offering both local produce and non-local produce that community members desire; and
  - accepting a variety of government assistance programs to pay for the produce:
    - SNAP benefits
    - WIC produce vouchers for local and non-local produce*
    - WIC Farmers Market Coupons and Senior Farmers Market Coupons – for only local produce*

* Would require policy waivers, currently seeking through FNS
Hartford Mobile Market Concept

- Mobile produce market conceptualized to serve the Hartford neighborhoods with least access to fresh produce – north and south end.
- Partnering with the Hartford Food System which will coordinate project operations.
- HHC to conduct and coordinate nutrition and health education, and the extensive evaluation.
- (Planned) evaluation:
  - feasibility, business sustainability,
  - increased produce access and intake,
  - impact on use of government food assistance programs
  - satisfaction of customers and farmers.
  - Dr. Pérez-Escamilla at Yale University to provide scientific leadership
- We believe that the implementation and rigorous evaluation of this “hybrid” model will inform others interested in developing similar strategies in their communities, and funders and policy makers interested in supporting them.
Hartford Mobile Market Current Status

- We intend to be operational before the end of the year.
- HHC conducted focus groups in Hartford’s north end to complete the formative research with community members.
- Hartford Food System has purchased a bus, and is in planning its renovation, including artistic design by a local youth group.
- Grants awarded: Hartford Hospital and the Harvard Pilgrim Healthcare Foundation, totaling $50,000.
- Grants outstanding: $175,000.
- Plans to submit to several other funders, including to support for operations and evaluation.
- Other supporters and stakeholders:
  - Hartford Department of Health and Human Services will provide in-kind: parking space, fuel, facilitation of permitting
  - CT legislature -interest expressed in providing financial support;
  - Executive Director of CT’s Farm Service Agency -has provided guidance;
Reflections on an Effective Community-Academic Partnership
Reflections on an Effective Community-Academic Partnership

Criteria Met:

- Shared planning from beginning of each project
- Shared leadership
- Shared budgets:
  - Example CEHDL, HHC 45% of budget
  - Budget shared equitably based on work performed
  - Indirect cost allocation provided to HHC based on its full negotiated rate
- Shared learning
- Shared data analysis
- Shared commitment to community benefit from research
- Shared dissemination – Example bibliography
Sample Bibliography from Partnership


2. D'Angelo, Karen A.; Chaparro, Carmen; Kornblum, Rita; Damio, Grace; and Pérez-Escamilla, Rafael (2013) "Development, Implementation, and Assessment of Health Equity Action Training (HEAT): Implications for Local Health Departments," Journal of Health Disparities Research and Practice: Vol. 6: Iss. 2, Art. 2.


Sample Bibliography from Partnership


Sample Bibliography from Partnership


Reflections on the Need for Continuous Community-Based Research Infrastructure
Reflections on the Need for Continuous Community-Based Research Infrastructure

## HHC Case Example

<table>
<thead>
<tr>
<th>Research Infrastructure</th>
<th>CEHDL 2009</th>
<th>Current Research Staff</th>
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<td>Dep. Dir./Comm. Core Dir. (HHC Res. Dir.)</td>
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<td>Research Core Scientist</td>
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<td>Study Coordinator</td>
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Reflections on the Need for Continuous Community-Based Research Infrastructure

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Successes and Challenges to CBOs in Securing and Sustaining Infrastructure for Community-Based Health Disparities Research

HHC Case Example - Strengths/Successes:

- Research part of organization’s mission, vision, core strategies since inception
- BOD Research Committee
- History of securing NIH grants directly, mostly HIV/Substance Abuse research
- History of authentic, equitable partnerships
- IRB established in 1990’s
- Adequate technology capacity for data management, storage
- Federally negotiated ICR
- Social justice orientation
- Relationship with community facilitates participant and staff recruitment
- Long-term research staff and leadership
- Four strategies: others offer support to research
Successes and Challenges to CBOs in Securing and Sustaining Infrastructure for Community-Based Health Disparities Research

HHC Case Example - Challenges:

- Loss of scientific capacity, and sometimes grants/funds when researcher leaves
- Competition with hard salaries and some other compensation at universities
- Competition with university infrastructure and idea that university is the “real research environment”
- Difficulty diversifying research topics without expert/PI already on staff
- Lack of consistent support staff to support grant writing, IRB
- Limited time among existing staff for producing publications and grant writing
- Limited resources for maintaining and updating/upgrading technology as needed
Conclusions/Recommendations

1. It is important for health disparities research to be conducted at the community level, involving communities from the point of generating research questions and planning studies.

2. For health disparities research to be conducted at the community level, research funding streams and research budgets must provide sustained support to communities for sustained infrastructure and for capacitation.

3. Community organizations are critical to successful health disparities research, and must be viewed as essential core partners in the research enterprise.

4. The expertise of community-based health disparities researchers should be shared with academic faculty and students.

5. There is a need for investment in professional development networks of community based organizations engaged in health research partnerships.
   - Community Campus Partnerships for Health convenes the Community Network for Research Equity & Impact that facilitates peer mentoring, skill-building and advocacy.
   - In Hartford, the Institute for Community Research is facilitating the building of a Community Research Alliance to address some of these issues. Similar processes are happening locally in other parts of the country.
Thank you!

¡Muchas gracias!