Mar 22nd, 10:45 AM

Building Capacity in Health Disparities Research

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Building Capacity in Health Disparities Research

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Director, Minority Health and Health Disparities Research Center
Senior Associate Dean for Diversity and Inclusion, School Of Medicine
University of Alabama at Birmingham
History of Health Disparities and Health Disparities Research

• In the 19th century, British statistician Edwin Chadwick demonstrated mortality differences between social classes living in Liverpool, England
  - Differences appeared to be due to poverty and lifestyle factors

• In 1849, German physician Rudolph Virchow argued that diseases are traceable to defects in society, and that the focus of medicine should shift to changing society

• At the end of the 1800s, French physician Louis Villerme recommended improving school and working conditions to reduce class differences in mortality

In 1984, the U.S. Department of Health and Human Services released a report on the health of the nation. The report indicated that the overall health of the nation showed significant progress, however, major disparities existed in the “burden of death and illness experienced by blacks and other minority Americans as compared with the nation’s population as a whole.” As a result, the U.S. Department of Health and Human Services established a task force on black and minority health.

By the end of the 20th century, research from a variety of sources were beginning to point to the reality that a complex series of factors played into an inequality of health among vulnerable and underrepresented populations in the United States.

“Of all the forms of inequality, injustice in health care is the most shocking and inhumane.”

-- Martin Luther King Jr.
Defining Health Disparities

A Health Disparity is defined by the National Institute of Minority Health and Health Disparities (NIMHD) as:

“A health difference that adversely affects disadvantaged populations, based on the categories of health outcomes.”
ADDRESSING HEALTH DISPARITIES: A COMMUNITY BASED APPROACH
Community-Based Cancer Projects

- Community Intervention Retention Strategy (CRIS)
  Funded by: National Cancer Institute (NCI)

- Enhancing Minority Participation in Clinical Trials (EMPaCT)
  Funded by: NIMHD

- Racial and Ethnic Approaches for Community Health (REACH 2010)
  Funded by: Centers for Disease Control and Prevention (CDC)

- Racial and Ethnic Approaches for Community Health (REACH for Better Health)
  Funded by: Centers for Disease Control and Prevention (CDC)
Community-Based Projects

Theoretical Framework Guided By Community-Based Participatory Research (CBPR)

- Coalition Development Model
- Community Health Advisor Model
- Community Empowerment
Community-Based Research

While great progress has been made in health promotion and disease prevention, we have failed in the translation of these efforts to practice. Some of the reasons:

- Academic institutions and communities may use different “tools” to address health promotion and disease prevention.
- Communities are often not consulted on the design and conduct of research projects.

Coalition Development Model

Bringing together state, academic, and community based organizations in order to mobilize and optimize resources to achieve a unified vision.
Empowerment Model

1970 - Paulo Freire

- Before community members address particular social change goals introduced from the outside, they must first be organized and empowered to address their own concerns and goals.

- It begins with a true dialogue in which everyone participates equally to identify common problems and solutions.

- Once the individual strengths and the shared responsibilities are identified, the group can work together toward a common goal - participatory process.
Community Health Advisors (CHAs) Model

Individuals who are trusted and respected by community members, who are “natural helpers” and have interest in improving the health status of individuals in their communities.
Community Health Advisors Model

Role of CHAs:

- Reach “hard to reach” populations
- Spread health education information
- Encourage healthy behaviors
- Help reduce barriers to health access
- Facilitate access to needed health services
A partnership approach that equitably involves, for example, community members, organizational representatives, and researchers in all aspects of the process.

Israel, et. al, 2003
COMMUNITY-BASED RETENTION INTERVENTION STUDY (CRIS)

Funding Agency: NCI
CRIS Objective

This study evaluated the effectiveness of a community-based intervention strategy based on Community Health Advisors (CHAs) to increase compliance and adherence in randomized clinical trial funded by NCI for management of abnormal Pap Smear (ALTS Trial). The study included the training and use of volunteers CHAs as research partners.
CRIS - ALTS Trial
ASCUS - Low Grade Triage Study (NCI)

- 1544 participants at UAB
- 63% A-A
- A-A 2.5 RR for HPV positivity
- Changed national guidelines for management of women with ASCUS-LSIL cytology
- 82% follow-up
CRIS Design and Methods

Two matched communities randomly assigned to Community Health Advisors (CHAs) supported intervention vs. control.
Training Community Health Advisors

To Market…. by “promoting” an opportunity for excellent medical care and treatment

To Mentor…. by teaching women about research and health issues

To Motivate…. by telephone calls, cards, and visits

To Monitor…. by recording their activities
Jefferson County Graduation Ceremony
CRIS Results

Adherence rates for scheduled clinic visits were significantly higher in the intervention group (80%) compared to the control group (65%) (P<000.1) These results indicated that volunteer CHAs can be effective in improving the retention and adherence of minority and low-income women in clinical trials.

<table>
<thead>
<tr>
<th>Attendance</th>
<th>Controls</th>
<th>CHA Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visit shows</td>
<td>449 (65)</td>
<td>642 (80)</td>
</tr>
<tr>
<td>Visit no-shows</td>
<td>238 (35)</td>
<td>163 (20)</td>
</tr>
<tr>
<td>Total no. of appointments</td>
<td>687</td>
<td>805</td>
</tr>
</tbody>
</table>

Abbreviations: CRIS, Community-Based Retention Intervention Study, CHA, Community Health Advisor.

a $P < .0001$. 
Adherence and Retention in Clinical Trials: A Community-Based Approach

Mona N. Fouad, MD, MPH; Rhoda E. Johnson, PhD; M. Christine Nagy, PhD; Sharina D. Person, PhD; and Edward E. Partridge, MD

BACKGROUND: The Community Health Advisor (CHA) model has been widely used to recruit rural and low-income, mostly African American women into clinical and behavioral research studies. However, little is known about its effectiveness in promoting retention and adherence of such women in clinical trials. METHODS: The Community-Based Retention Intervention Study evaluated the effectiveness of a community-based intervention strategy using the CHA model and the empowerment theory to improve the retention and adherence of minority and low-income women in clinical trials. The research strategy included the training and use of the volunteer CHAs as research partners. The target population included women participating in the University of Alabama at Birmingham clinical site of the Atypical Squamous Cells of Undetermined Significance-Low-Grade Squamous Intraepithelial Lesion (ASCUS-LSIL) Triage Study (ALTS), a multicenter, randomized clinical trial. Two communities in Jefferson County, Alabama, that were matched according to population demographics were identified and randomly assigned to either an intervention group or a control group. Thirty community volunteers were recruited to be CHAs and to implement the intervention with the ALTS trial participants. In total, 632 ALTS participants agreed to participate in the project, including 359 in the intervention group, which received CHA care, and 273 in the control group, which received standard care. RESULTS: Adherence rates for scheduled clinic visits were significantly higher in the intervention group (80%) compared with the control group (65%; \( P < .0001 \)). CONCLUSIONS: The results indicate that volunteer CHAs can be trained to serve as research partners and can be effective in improving the retention and adherence of minority and low-income women in clinical trials. Cancer 2014;120(7 suppl):1106-12. © 2014 American Cancer Society.

KEYWORDS: clinical trials, adherence, retention, minority women, underserved women, African American women.
ENHANCING MINORITY PARTICIPATION IN CLINICAL TRIALS

(EMPaCT) Phase II

Funding Agency: NIMHD
EMPaCT: Filling a Need

- Developed in response to data from UAB indicating a gap in the number of African Americans (AAs) and other underserved groups diagnosed with cancer and the number who enroll in trials
- AAs in UAB catchment area = 23.2%
- AA participants in UAB clinical trials = 11.4%
EMPaCT I
Assessment of Barriers, Impediments, and Facilitators

➢ Funded by National Institute on Minority Health and Health Disparities as RC2 MD004797

➢ Regional in focus, national in scope

➢ Consortium of five regional leaders:
  o East: Johns Hopkins University, Dr. Jean Ford
  o Southeast: University of Alabama at Birmingham, Dr. Mona Fouad
  o Midwest: University of Minnesota, Drs. Selwyn Vickers & Jasjit Ahluwalia
  o Southwest: M.D. Anderson Cancer Center, Dr. Lovell Jones
  o West: University of California Davis, Dr. Moon Chen
EMPact I $\rightarrow$ EMPact II
Strategies for Improving Minority Recruitment

EMPact I

Qualitative Needs Assessment
- Outstanding minority recruitment needs
  - Barriers/facilitators
  - Best practices

EMPact II

Quantitative Needs Assessment
- Aggregate minority recruitment data and data collection methods

Menu of adaptable options for optimization of minority recruitment and retention

EMPact II Specific Aims

- Web-portal
- Patient Navigation
- Clinical Trials Ombudsman
EMPaCT: Objective and Methods

Objective for EMPaCT:
➢ Develop an innovative approach to enhance minority participation in cancer trials conducted mainly at UAB CCC

Methods to accomplish the objective:
➢ Identify and train Community Health Advisors (CHAs) as patient navigators
EMPaCT: Program Implementation

- Navigators attend weekly research team meetings and Clinical Trial Research Study meetings
  - Learn about new research protocols
  - Learn about safety issues
  - Provide feedback from patients (generally)
  - Obtain new referrals

- Diverse group of patients referred to EMPaCT, including:
  - Gastrointestinal
  - Gynecological Oncology
  - Head and Neck Cancers
  - Hematology Oncology
  - Lung
African American patients with cancer receive clinical trial education in the clinic waiting rooms.

Clinical research nurses contact EMPaCT navigators when there is a African American patient considering participation in a clinical trial and/or has been recruited but the patient needs support.

Navigator meets with the patients, conducts a needs assessment, and begins to provide support to patients to overcome barriers to trial participation.
EMPaCT: Program Implementation

Clinical trial education using NCI booklets and project specific materials

Counseling on participant’s rights

Review of trial treatment regimens

Trial participation calendar
EMPaCT: Program Implementation

- Community partnerships (gas cards, meal vouchers etc.)
- Identifying lodging options and making special arrangements
- Referral to appropriate service provider
- Counseling patients to be proactive
EMPaCT: Program Implementation

- Bridging communication gaps
- Orientation to appropriate clinical staff and resources
- Problem solving to overcoming barriers
- Referral to other support services
EMPaCT: Program Implementation

Direct patient advocacy

Social support

Visits in the hospital
## EMPaCT: Results

### Services Provided by Clinic/Site:

<table>
<thead>
<tr>
<th>Clinic</th>
<th>Transportation</th>
<th>Lodging</th>
<th>Insurance</th>
<th>Social and Emotional Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bone Marrow Transplantation</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>43</td>
</tr>
<tr>
<td>Gastrointestinal/Genitourinary</td>
<td>62</td>
<td>3</td>
<td>0</td>
<td>348</td>
</tr>
<tr>
<td>Gynecologic Oncology</td>
<td>137</td>
<td>15</td>
<td>4</td>
<td>913</td>
</tr>
<tr>
<td>Head and Neck</td>
<td>27</td>
<td>7</td>
<td>0</td>
<td>223</td>
</tr>
<tr>
<td>Hematology Oncology</td>
<td>168</td>
<td>13</td>
<td>2</td>
<td>958</td>
</tr>
<tr>
<td>Invasive Ductal Breast Carcinoma</td>
<td>394</td>
<td>10</td>
<td>1</td>
<td>1,463</td>
</tr>
<tr>
<td>Cooper Green Mercy Hospital</td>
<td>28</td>
<td>0</td>
<td>0</td>
<td>86</td>
</tr>
<tr>
<td>Lung</td>
<td>25</td>
<td>12</td>
<td>0</td>
<td>415</td>
</tr>
<tr>
<td>Neuro Oncology</td>
<td>25</td>
<td>5</td>
<td>1</td>
<td>191</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>21</td>
</tr>
<tr>
<td>Radiation Oncology</td>
<td>45</td>
<td>2</td>
<td>0</td>
<td>344</td>
</tr>
<tr>
<td>Solid Tumors</td>
<td>12</td>
<td>3</td>
<td>0</td>
<td>147</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>927</strong></td>
<td><strong>71</strong></td>
<td><strong>8</strong></td>
<td><strong>5,152</strong></td>
</tr>
</tbody>
</table>
EMPaCT: Results

Percentage of new patients referred to IMPaCT from Oncology Clinics by year:

- 5.5% in 2007
- 14.0% in 2008
- 12.0% in 2009
- 13.4% in 2010
- 12.7% in 2011
- 14.1% in 2012
- 13.8% in 2013
- 16.6% in 2014
EMPaCT: Results

Percentage of referrals for clinical trial and IMPaCT:

![Graph showing percentage of referrals for clinical trial and IMPaCT over the years]
EMPaCT: Results

Barriers Addressed

➢ Transportation – addressed 448 times
➢ Lodging – addressed 37 times
➢ Social Support - addressed 2868 times
  o Appt. reminders; confirmed plans; escort/guest services; emotional support; paperwork assistance; resource inquiry; ‘counseling’; referral to other supportive services such as Look Good Feel Better, Reach to Recovery; etc.
EMPaCT Patient Navigators Intervention

A Patient Navigator model to enhance participation of African American cancer patients in therapeutic clinical trials at the UAB Comprehensive Cancer Center.

- 424 AA cancer patients were referred to EMPaCT. Of those eligible for a clinical trial (N=378), 304 (80.4%) enrolled in a trial and 272 (72%) consented to receive PN support. 74.5% completed the trial, compared to 37.5% of those not receiving PN support.

- The difference in retention rates between the two groups was statistically significant (p< 0.001).

- Participation of AAs in therapeutic cancer clinical trials increased from 9% to 16%.
EMPaCT Outcomes

Enrollment Outcomes for African American Patients Referred to the Patient Navigation Program by Year, 2006-2014.
EMPaCT Outcomes

Cancer Clinical Trial Completion Rate According to PN Program Enrollment
Patient Navigation As a Model to Increase Participation of African Americans in Cancer Clinical Trials

Mona N. Fouad, MD, MPH, Aras Acemgil, MDA, Sejoung Bae, PhD, Andres Forero, MD, Nedra Lisovicz, PhD, Michelle Y. Martin, PhD, Gabriela R. Gottes, PhD, Edward E. Partridge, MD, and Salwyan M. Vekres, MD

Abstract

Purpose

Less than 10% of patients enrolled in clinical trials are minorities. The patient navigation model has been used to improve access to medical care but has not been evaluated as a tool to increase the participation of minorities in clinical trials. The Increasing Minority Participation in Clinical Trials project used patient navigators (PNs) to enhance the recruitment of African Americans for and their retention in therapeutic cancer clinical trials at a National Cancer Institute-designated comprehensive cancer center.

Methods

Lay individuals were hired and trained to serve as PNs for clinical trials. African American patients potentially eligible for clinical trials were identified through chart review or referrals by clinic nurses, physicians, and social workers. PNs provided two levels of services: education about clinical trials and financial support for patients who enrolled in clinical trials.

Results

Between 2007 and 2014, 424 African American patients with cancer were referred to the Increasing Minority Participation in Clinical Trials project. Of those eligible for a clinical trial (N = 378, 304 [80.6%] enrolled in a trial and 72 [19.4%] consented to receive patient navigation support. Of those receiving patient navigation support, 74.5% completed the trial, compared with 37.5% of those not receiving patient navigation support. The difference in retention rates between the two groups was statistically significant (P < .001). Participation of African Americans in therapeutic cancer clinical trials increased from 9% to 16%. 

University of Alabama at Birmingham, Birmingham, AL.
RACIAL AND ETHNIC APPROACHES TO COMMUNITY HEALTH

(REACH 2010)

Funding Agency: Centers for Disease Control and Prevention
REACH 2010 Mission

To bring together public and community based organizations in order to mobilize and optimize resources in African American communities and eliminate the disparity in breast and cervical cancer mortality between African American and Caucasian women.
REACH 2010 Target Communities
REACH 2010

Step I: (Coalition Building)
Form a coalition of public and community based organizations in order to mobilize and optimize resources in African American communities.

Step II: (Community Capacity Building)
Establish networks of community volunteers to serve as Community Health Advisors (CHAs) in the nine REACH counties.
REACH 2010

Step III: (Assessment of community needs)
Conduct one focus group in each county to assess community needs in relation to breast and cervical cancer.

Step IV
Develop a population-specific breast and cervical cancer screening and management Community Action Plan (CAP)
REACH 2010

Individual Barriers:

➢ Women associated breast and cervical cancer with “fear, death, depression, and danger.”
➢ Although women were aware of early detection and screening for cancer, they had a fatalistic view of their health outcomes once they had cancer.
REACH 2010

Community System Barriers:

➢ Lack of family or community support
➢ Transportation
➢ Lack of access to primary care physicians
Health Care Provider Barriers:

- Women indicated that they saw health care providers as the source of much of the problem.
- They felt that inadequate providers made “good health care” difficult.
- They spoke of health providers who belittled their complaints, overbooked appointments, and kept them waiting.
REACH 2010

REACH focused on:

➢ Capacity building
➢ Coalition building

- Community-based organizations
- Faith-based organizations
- Academic institutions
- State Health Department
- Private foundations
- Health care system

Theresa Wynn (6th from left) with REACH County Coordinator Sherry Kay Talor (far right) and the Choctaw County Community Health Advisors
REACH 2010

- 169 community health advisors
- 23 health professionals
- 49 church representatives
REACH 2010

Methods:

➢ Completed 8 week structured training
  o Skill building
  o Breast and cervical cancer education
  o Conducting community assessment
  o Disseminating health messages

➢ Monthly maintenance meeting
REACH 2010

Methods:

➢ Using the Stages of Change Theory, deliver appropriate and motivating messages to assist women in adhering to mammography and pap smear screening regimens
  o Stage 1 (never had a screening)
  o Stage 2 (infrequent screening)
  o Stage 3 (regular screening)
Methods:

- Identified 2800 women and assessed their breast and cervical cancer screening behavior
- Promoted screening and disseminate other health messages through monthly contact
- Conducted cancer awareness community events
- > 1500 women continue in the intervention after 5 years.
REACH 2010

Objective: To decrease the number of women (never screened) while increasing the number of women (infrequently screened) and (regularly screened) in an underserved rural, high minority region.

Sample: 1531 rural AA women residing in 8 Black Belt counties

Results (all p-values < .0001): *AJPH Dec. 2010*
- Proportion never screened: 14% to 4%
- Proportion infrequently screened: 16% to 20%
- Proportion adhering to screening guidelines: 70% to 76%
REACH 2010

Reduction in Disparity of Mammography Screening Rate (1998-2006)
Objectives. We assessed the impact of a theory-based, culturally relevant intervention designed to increase mammography screening among African American women in 8 underserved counties in Alabama.

Methods. Using principles derived from the Stages of Change, Community Health Advisor, and Community Empowerment models, we developed strategies to increase mammography screening. Trained volunteers (N = 143) provided tailored messages to encourage adoption and maintenance of mammography screening. We collected baseline and follow-up data on 1513 women in the communities targeted for the intervention. Our goal was to decrease the number of women in stage 1 (never screened) while increasing the number of women in stage 2 (infrequently screened) and stage 3 (regularly screened).

Results. At baseline, 14% (n = 211) of the women were in stage 1, 16% (n = 247) were in stage 2, and 70% (n = 1055) were in stage 3. After the 2-year intervention, 4% (n = 61) of the women remained in stage 1, 20% (n = 306) were in stage 2, and 76% (n = 1146) were in stage 3.

Conclusions. Tailored motivational messages and peer support can increase mammography screening rates for African American women.
The REACH Coalition

A healthy living initiative led by the UAB MINORITY HEALTH AND HEALTH DISPARITIES RESEARCH CENTER

Key Community Leaders Kingston & North Avondale
REACH Goals

Reduce the disparities in chronic disease and associated risk factors between African Americans and Whites by addressing the two drivers of disparities – nutrition and physical activity.

Focus on pre-existing policy, systems, and environmental (PSE) strategies that have shown limited improvement in our priority population.
REACH for Better Health

Priority Population

• Large-scale interventions reaching 75% (116,000) of the African Americans living in Birmingham
• Targeted interventions in 2 vulnerable U.S. Census tracts
  Kingston (Census Tract 5)
• North Avondale (Census Tract 6)

Approach

Community-based participatory approach
Coalition capacity building

• Active coalitions and partnerships with a history of successfully working together on issues related to health or health disparities
• Poised to start implementation from year 1
• CDC approved strategies that aligned with needs assessment
Objectives

Increase the number of people with access to physical activity opportunities from 51,000 to 116,000 by September 2017\textsuperscript{a,b}

Increase the number of people with improved access to environments with healthy food and beverage options from 22,000 to 100,000, by Septembers 2017\textsuperscript{a,b}

REACH has impacted over 500,000 people in Jefferson County, AL

\textsuperscript{a.} Community commons
\hspace{1em} Community Health Needs Assessments: identify assets and potential disparities in your county/region related to community health & well-being
\hspace{1em} Vulnerable Populations Footprint:Find areas in your community with low educational attainment and high poverty.
\hspace{1em} Location Opportunity Footprint: Find areas of opportunity in your community. Map housing and transportation costs, school proficiency and availability of jobs.

\textsuperscript{b.} Data Source: American Community Survey
Strategies and Outcomes

Access to Healthy Foods

Increase the number of food-related businesses purchasing fresh produce through the Urban Food Project’s produce distribution system from 15 to 30.

Met and exceeded goal by 48.

Increase the number of JCDH regulated childcare centers that have implemented a healthy food option as required by the revised Childcare Regulations 0 to 100% (0 to 138).

Met goal; of the childcare centers that were scored, ≥80% were compliant w/revised regulations.
Strategies and Outcomes

Improved Access to Opportunities for Physical Activity

Increase the number of YMCA branches and afterschool readiness sites that implement a CATCH curriculum from 4 to 10.

Met and exceeded goal by 11, inclusive of YMCA & afterschool readiness sites.

Increase the number of cities that include elements of Safe Routes To School into a city policy from 0 to 1.

Objective met in partnership with United Way of Center Alabama and Complete Streets coalition. City ordinance approved March 6, 2017. REACH supported Complete Streets logo, tagline and infographic.
Strategies and Outcomes

Improved Access to Opportunities for Physical Activity

Increase the number of primary care providers that prescribe exercise as medicine from 0 to 5.

Met and exceeded by 18 (JCDH providers); 16,948 prescriptions have been written

Increase the number of neighborhoods with identifiable walking trails from 0 to 5.

Met and exceeded. Parks Rx signs are installed in 95 Birmingham & Jefferson County parks. 139 park maps on Reachforbetterhealth.com
1. Get a prescription for ParksRx from your healthcare provider.
2. Visit www.REACHforbetterhealth.com
3. Enter your zip code
4. Click
   Pick your park
   Exercise in the park and share outcomes with your healthcare provider.

PARKS Rx
Your Prescription For Better Health

www.REACHforbetterhealth.com/ParksRx
Made possible with funding from the Centers for Disease Control and Prevention.
Adult & pediatric prescriptions in English & Spanish

Prescriptions may be downloaded from the website

Prescription directs patients to 139 parks & trails in Jefferson County that are most conducive for exercise
The Story of REACH
QUESTIONS?