Patient Centered Care Collaboration (*PCCC*) in Chicago: Health Empowerment and Lifestyle Program (*HELP*) for African Americans with Obesity, Hypertension and/or Diabetes

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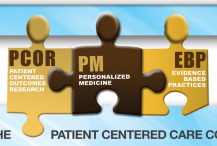

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Presenter Disclosures

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No Relationships To Disclose

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  - Westat Research Inc. and the PCCC research team
- The 3 Chicago health centers (TCA, Chicago Family Health Center, JIL Medical Consultants) and their staff for pilot implementation.
- Midwest Latino Health Research Training and Policy Center at Jane Adams College of Social Work at UIC
- PCCC Stakeholders.

Objectives

- Describe Patient Centered Care Collaboration Project and the Chicago educational model with its results.
- Discuss challenges and lessons learned in educating low income African Americans with low health literacy.

Presentation outline

- PCCC Background
- PCCC Implementation in Chicago: HELP Pilot
- Methods
- Results
- Discussion
  - Successes- Successful Stories
  - Challenges and Limitations
  - Lessons Learned
  - Recommendations and Next Steps
- Conclusion

Background

- Innovative initiative of the USDHHS-Office of Minority Health.
- Calls for developing and pilot-testing promising practices to reduce disparities in obesity, type 2 diabetes and hypertension through building partnerships with diverse sectors.
- Time Period: July 2010- July 2013

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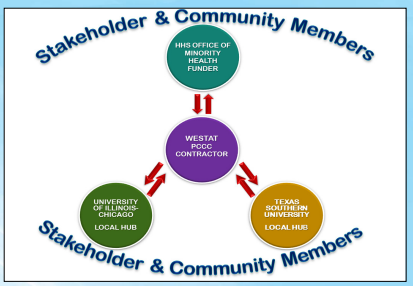
Leadership structure of the PCCC



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PCCC GOAL

- The overarching goal of the PCCC Initiative was to explore how current advances in comparative effectiveness research (CER) may be used to reduce health disparities among vulnerable populations.
- In this initiative, evidence-based practices that have been utilized and proven effective in prior CER findings were translated and disseminated among minority serving health providers and racial and ethnic minority patients with diabetes, hypertension, or obesity or a combination of these conditions

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PCCC Components

- Infrastructure Development, Capacity Building, and Stakeholder Engagement;
- Selection of CER-informed Interventions for Translation and Dissemination;
- Translational Activities;
- Pre-Implementation Preparation for the Interventions;
- Implementation of the CER-informed Interventions;
- Evaluation; and
- Diffusion planning/Promoting Adoption/Scale Up.

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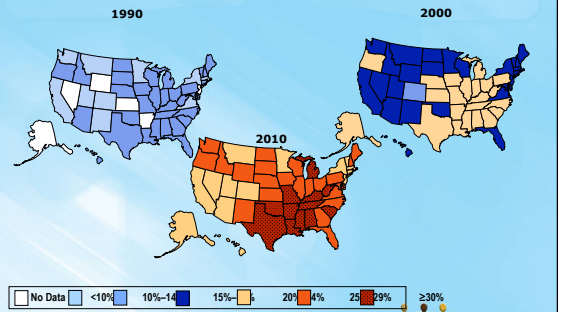
Why PCCC on Obesity, Hypertension &Diabetes?

BRFSS, 1990, 2000, 2010

Obesity Trends (*BMI ≥30, or about 30 lbs. overweight for 5'4" person)



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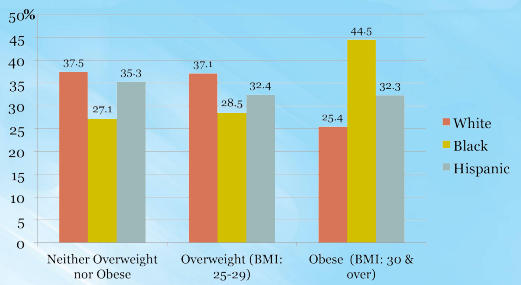
Overweight and Obesity (BMI)-Illinois, 2010
Weight Classification by Body Mass Index (BMI)



Source: BRFSS. CDC.

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Higher BMI Associated with Increased Risk of Developing Chronic Diseases

Disease	BMI 25 or less	BMI 25 to 30	BMI 30 to 35	BMI 35 +
Arthritis	1.00	1.56	1.87	2.39
Heart Disease	1.00	1.39	1.86	1.67
Diabetes (Type 2)	1.00	2.42	3.35	6.16
Gallstones	1.00	1.97	3.30	5.48
Hypertension	1.00	1.92	2.82	3.77
Stroke	1.00	1.53	1.59	1.75

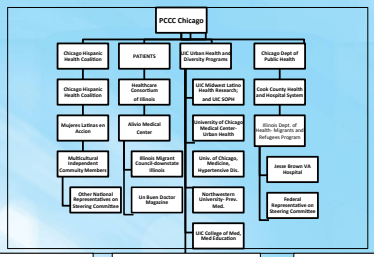
Source: Centers for Disease Control. Third National Health and Nutrition Examination Survey. Analysis by the Lewin Group, 1999.

Selected Health Disparities in Chronic diseases by Race & Ethnicity, for Illinois, 2010

Selected Chronic Diseases	IL Whites	IL Black	IL Hispanic
	%	%	%
Diabetes	7.6	12.4	10.9
CVD-Coronary Heart Disease	4.4	4.2	1.9
CVD Heart Attacks	4.3	4.2	3.4
Stroke	2.8	4.2	2.3

Sources: BRFSS, CDC, Kaiser Family Foundation

PCCC Chicago hub stakeholders: potential networks for engagement



Community Based Organizations, Individual Community Members, Health Care Systems	Academic Partners- Colleges/Universities	Government Agencies at the State and Federal Levels

Engagement and Dissemination Activities

- Westat and both Hubs activities:
  - ✓ Virtual Training: Webcasts/Webinars/WebEx and Conference Calls
  - ✓ In-person training sessions
  - ✓ Technical assistance sessions tailored to meet the hubs' needs.
- Chicago Hub activities:
  - ✓ Conference calls
  - ✓ Meetings: individual and group
  - ✓ Local and national conferences
  - ✓ Networking seminars
  - ✓ Presentations: oral and poster

PCCC - Chicago Hub

- Housed in the Urban Health and Diversity programs at the School of Public Health, University of Illinois at Chicago (UIC)
- The hub provided the infrastructure for planning and coordinating the implementation of the intervention, and other PCCC activities such as engaging local communities through meetings and special training events.

PCCC - Chicago Hub

Minorities in Chicago:

- Live in concentrated areas or identifiable neighborhoods.
- Have faced barriers of poverty and employment in marginal economic sectors, resulting in Medicaid eligibility or being uninsured.
- Many have been displaced but return to their old neighborhoods for Health services, ethnic shopping, religious and cultural organizations who have established a record of working with minority populations in their home neighborhoods.

PCCC - Chicago Hub

To address the 3 chronic conditions requested by PCCC:

UIC -SPH -UHDP implemented the Health Empowerment and Lifestyle Program (HELP), developed by the Midwest Latino Health Research Training and Policy Center at UIC.

HELP

- An expansion of the existing Diabetes Empowerment Education program (DEEP)* plus other modules that address hypertension and weight management.
- Incorporates educational curriculum for adults with empowerment principles, and participatory techniques to address the health literacy and self-management needs of Hispanic/Latino and African American minorities with type 2 diabetes with hypertension or obesity.
- Has 2 components: Train –the- Trainer & multisession patient education

* Source: Castillo, 2010

Training the Trainers

- 20-hour workshop
- Community health workers and other health professionals
- Teaches CHWs how to educate patients in the implementation of the curriculum
- Uses participatory approaches
- Training for Blood pressure monitors, weight scales, BMI calculation charts, tape measures and the use of data collection and reporting

Educational Curriculum

Educate participants regarding:

1. Disease impact on the body ;
2. Disease risk factors and methods for addressing them; biomedical markers and their benchmarks (e.g., HbA1C, blood pressure, and weight);
3. Benefits of monitoring and managing diet, physical activity, and medication; and the cultural differences associated with the management of diabetes, hypertension, and obesity;
4. All materials and activities were designed to be culturally and linguistically appropriate for African American and Latino populations in the Chicago community.

Program Methodology

- Based on empowerment theory principles
- Freire's principles of adult education
- Participatory techniques
- Delivered by community health promoters- peer educators

Module Contents

- 1: Beginning session- Understanding the human body
- 2: Understanding risk factors of diabetes and Cardiovascular diseases.
- 3: Monitoring your body
- 4: Get up and Move! Chronic Disease & Physical activity
- 5: Management of diabetes and cardiovascular through nutrition and meal planning
- 6: Diabetes and Cardiovascular complications: Identification and prevention
- 7: Medication and medical care
- 8: Obesity and weight management
- 9: Coping with chronic disease: Mobilizing your family and friends

Class Design

For Facilitators

- Goals
- Learning Objectives
- Preparation and Materials Checklist
- Content Outline
- Colored boxes guide educational activities
- Evaluation

Lesson Plan

- Opening/ Discuss what will be covered
- Content/Activities
- Review
- Weekly Action Plan
- Closing

Chicago Hub Stakeholder and Clinic Recruitment Strategies

- Identifying potential stakeholders including clinics for pilot implementation
  - Face to face and telephone contacts with community and professional individuals that we have a history of collaboration and trust
  - Identifying individuals that have knowledge, experience and interest in the topic areas to be addressed and/or have one of the conditions
  - Maintain on-going communication with community members in your advisory committee
- Issues and challenges with recruitment
  - Identifying leaders in the community but they are too busy
  - Difficulties in scheduling face to face or conference calls
  - People want to be hand-on on concrete activities, so delay in implementation led to loss of interest in project activities.
  - Maintenance of expectations & timeline for implementation, evaluation and dissemination for community adoption (e.g., IRB process).

Intervention Calendar

- October 2012: Identified 3 clinics at the south side of Chicago:
  1. **TCA Health, Inc.**
  2. **Damen /Garfield Medical Center/JIL Medical Consultants**
  3. **Chicago Family Health Center- Pullman**
- November 2011:
  - Hired Project Manager, CHW
  - HELP Training: Project Manager, CHW, and patient navigators
- December 2012:
  - IRB approval/amendments
  - IRB Training: Project Manager, CHW, patient navigators
  - Patient Recruitment started by the patient navigators
- January 2013: Implementation

Chicago Hub Staff

- PI
- 2Co-PIs
- Master Trainer
- Project Manager
- Fiscal Manager
- 1CHW
- 3 Patient Navigators and 3 clinic contacts

Implementation Calendar

- January 7 to March 29/ 2013; 5 cohorts at the 3 clinics
- Week 1 & 2: Consents, screenings for eligibility, pre intervention survey, measurements
- Week 3-11: Two hour Education classes conducted by a Latino CHW assisted by the Patient Navigator from each clinic
- Week 12: Post implementation survey and measurement; End of pilot celebration
- Week 13: Focus groups; Stakeholders meeting

Pilot Study Goals

1. Increase knowledge of diabetes, hypertension, obesity
2. Improve self-management skills (starting with self-monitoring)
3. Deal with psychosocial issues
4. Reduce A1c, blood pressure, waist circumference, weight
5. Short- and long-term behavioral change

Study Design

- Non-experimental pre-posttest single group design

Criteria for Target Population

Total number of participants:	**40-50**
Eligibility criteria:	☐ African- Americans and English speaking Hispanics/Latinos ☐ 18-65 years ☐ Type 2 diabetes (A1C>7.5), hypertension >140/90 and/or overweight or obesity (BMI> 25 ☐ Not traveling during the intervention ☐ Ability to develop self-care skills
Exclusion criteria:	☐ Psychiatric diagnosis and/or cognitive impairment ☐ Heavy users of alcohol or substance abuse ☐ History of seizure disorder ☐ Myocardial infarction within the past 6 months ☐ Terminal illness ☐ Pregnant

Evaluation: Key Measures

- Quantitative
  - Questionnaires: Knowledge; Summary of Self-Care Activities
  - Biomarkers- Clinical Outcomes: HbA1C; BP; weight, BMI; waist circumference
- Qualitative
  - Participants' Focus Groups- 3
  - Staff surveys (reported to Westat directly)
  - Staff Interviews (Westat external evaluator)

Pilot Implementation: Activities at the centers

- ✓ **Application of forms: Consents, screenings for eligibility, pre and post intervention survey and measurements**
- ✓ **Curriculum implementation**
- ✓ **Reminders, follow up, enforcement**
- ✓ **Participant Reimbursement and receipts**
- ✓ **Snacks**
- ✓ **Participant end of pilot celebration and awarding certificates**
- ✓ **Focus group**

CHW Contribution

- The CHW was Hispanic/Latino and all of the participants were African American.
- There was a consistent opinion amongst those surveyed (participants, implementation staff, facility administrators, and local hub members) that knowledge, passion, and caring attitude of the CHW was more important than being from the same culture as the participants.
- Patient's own words regarding CHW (Instructor):
  - ✓ Approachable; have a personal touch; teaches and look at you as a person; made sure that you understood; & trustworthy
  - ✓ Provide illustration so patient takes it seriously
  - ✓ Explains in lay language, in depth (time and details)
  - ✓ Provide time to ask questions, hands on activities, medication information, Learn how disease affects different parts of the body
  - ✓ CHW bridges the gap between doctor and patient

Stakeholders; Dissemination; Reporting activities

- ✓ **Stakeholders calls and webinars**
- ✓ **End of project meeting reception for breakfast and providing awards ceremony**
- ✓ **Event & calendar coordination,**
- ✓ **Project supervision,**
- ✓ **Westat reports, call meetings and written reports**
- ✓ **Steering Committee call meetings**
- ✓ **Dissemination of pilot update and materials to stakeholders and community**
- ✓ **Dissemination through presentations including academic conferences and seminars**

Data Collection & Analysis

- **Pre-test and post-test screenings, surveys, and measurements were collected, data were entered and reported electronically to Westat.**
- **Participant attendance and follow up data reported to Westat through a tracking system to monitor participant progress and program attendance.**
- **Focus groups recordings & notes were conducted by master trainer and project manager and submitted to Westat for analyses. Westat external evaluator observed focus groups.**
- **Stakeholders engagement reports were submitted to Westat**
- **Staff Surveys were reported directly to Westat**
- **Staff interviews were conducted and reported to Westat by Westat external evaluator**

Westat Reporting Strategies

- Maintain communication—Communicate on a routine basis with local hub staff
- Maintain a schedule—Identify and set a schedule for completing activities and reaching milestones, and identifying staff responsible for these activities;
- Maintain commitment to the initiative—Ensure that resources remain available to implement the intervention
- Provide technical assistance/offer assistance to resolve issues—Provide a platform for local hub staff to discuss impediments to implementation.

Results

Variable	Number (N)	Followup rate (%)
Number of participants completing the screening survey	53	-
Number of participants completing the baseline intake survey	45	-
Number of participants completing the post-intervention survey	38	84

Characteristics of PCCC participants at baseline by specific site

Variable	Total all sites N=45		Chicago FAMILY HEALTH CENTER N=15		Garfield Damen Medical Center N=10		TCA Health Inc. N=20	
Race and Ethnicity	N	(%)	N	(%)	N	(%)	N	(%)
Race/ethnicity (n=45)[a]								
African American	44	(97.8)	14	(93.3)	10	(100)	20	(100)
Hispanic/Latino	1	(2.2)	1	(6.6)	0	(0)	0	(0)
Sex (n=45)[a]								
Male	12	(27)	3	(20)	5	(50)	4	(20)
Female	33	(73)	12	(80)	5	(50)	16	(80)
Age (n=45)[a]								
18-44	6	(13.3)	1	(6.26)	2	(20)	3	(15)
45-59	27	(60)	9	(60)	6	(60)	12	(60)
60-69	12	(26.7)	5	(33.3)	2	(20)	5	(25)
Country of birth (n=45)[a]								
U.S.	45	(100)	15	(100)	10	(100)	20	(100)
Mexico	0	(0)						
Primary Language (n=45)[a]								
English	45	(100)	15	(100)	10	(100)	20	(100)
Spanish	0	(0)						
Education level (n=42)[a]								
Middle school or lower	3	(7)	0		1	(11)	2	(11)
Some high school	6	(14)	2	(14)	1	(11)	3	(16)
High school graduate	15	(36)	7	(50)	3	(33.5)	5	(26)
Some college	14	(33)	4	(29)	3	(33.5)	7	(37)
College graduate	2	(5)	0		1	(11)	1	(5)
More than 16 years	2	(5)	1	(7)	0		1	(5)

Outcomes (N=38)

Index	Baseline M (SD)	Post-test M (SD)	P value
A1C	8.35 (2.41)	7.93 (1.86)	< .05
Weight	222.53 (41.98)	221.00 (42.92)	ns
BMI	36.12 (7.68)	36.11 (8.31)	ns
Systolic blood pressure	136.26 (14.92)	126.47 (14.05)	< .01
Diastolic blood pressure	84.66 (9.4)	82.24 (9.41)	ns
Waist circumference	45.71 (7.02)	44.24 (6.46)	ns

Knowledge Questionnaires (N=38)

Condition	Percentage of correct answers Baseline M (SD)	Post M (SD)
Diabetes	78%	82%
Overweight/obesity	73%	76%
High blood pressure	72%	83%

(Westat Report)

Summary of Self-Care Behaviors (N=38)

Characteristic	Baseline M (SD)	Post M (SD)
Self-care activities: Diet[a]	**3.63 (.74)**	**4.01 (.99)**
Eating 5 or more servings of fruits and Vegetables	3.86 (2.15)	4.55 (1.78)
Space carbohydrates evenly throughout the day	3.95 (2.0)	4.16 (2.19)
Eat high fat foods (reversed)	3.66 (1.99)	3.97 (1.79)
Add table salt to meals (reversed)	4.26 (2.71)	5.39 (2.18)
Avoid canned/pre-packaged food	2.38 (2.20)	1.95 (2.32)
Smoking during last 7 days		
Number of cigarettes in past week	2.26 (4.85)	1.73 (3.72)
Self-care activities: Exercise[a]	**3.16 (2.06)**	**4.33 (2.00)**
Participate in at least 30 minutes of physical activity	3.50 (2.21)	4.74 (2.08)
Participate in an exercise session other than daily living	2.82 (2.56)	3.92 (2.67)
Self-care activities: Blood Sugar Testing[a]	**3.11 (2.34)**	**4.02 (2.42)**
Test blood sugar	4.13 (2.89)	3.13 (2.76)
Test blood sugar the number of times that the provider recommended	3.13 (2.75)	4.08 (2.92)
Test BP at home	2.05 (2.66)	3.00 (3.04)
Self-care activities: Foot Care[a]	**3.79 (2.80)**	**5.41 (2.04)**
Check your feet	4.26 (2.79)	5.55 (2.10)
Inspect inside of shoes	3.32 (3.09)	5.26 (2.46)
Self-care activities: Medication Use[a]	**5.47 (2.55)**	**5.78 (2.29)**
Take recommended diabetes medication	5.29 (2.80)	5.87 (2.34)
Take other recommended medications	5.76 (2.52)	5.68 (2.38)

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Self-efficacy in management of health conditions (N=38)

Condition	Baseline M (SD)	Post M (SD)
Confidence in Self-Management[a]	2.40 (0.42)	2.71 (0.29)
1. Know how to read and understand food labels	2.47 (0.69)	2.89 (0.31)
2. Can follow diet	2.34 (0.71)	2.68 (0.47)
3. Can choose appropriate foods	2.22 (0.67)	2.66 (0.67)
4. Can exercise 15-30 minutes, 4-5 times a day	2.34 (0.73)	2.63 (0.59)
5. Can prevent low blood sugar level	2.46 (0.70)	2.47 (0.65)
6. Know what to do when high blood sugar	2.42 (0.69)	2.76 (0.54)
7. Judge when to visit doctor	2.64 (0.59)	2.87 (0.34)
8. Can control diabetes	2.39 (0.68)	2.63 (0.49)
9. Know how to make healthy food choices	2.39 (0.73)	2.76 (0.43)
10. Know how to control blood pressure	2.37 (0.68)	2.68 (0.57)

[a] 1=Not at all confident, 2=Somewhat confident, 3=Very confident.

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Quality of Life (N=38)

Interfered with...	Baseline M (SD)	Post M (SD)
Negative Feelings[a]	0.87 (0.67)	0.75 (0.62)
Discouraged by health problems	0.74 (0.76)	0.63 (0.75)
Fearful about future health	0.84 (0.82)	0.68 (0.77)
Health is a worry in life	0.95 (0.77)	0.84 (0.68)
Frustrated by health problems	0.95 (0.80)	0.84 (0.72)

[a] 0=Not at all, 1=Some of the time, 2=Most of the time.

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Participants' Focus Groups

- Reflected participant engagement & positive feedback in regards to the implementation, CHW and Patient Navigators.
- Participants expressed their aspirations to:
  - Maintain the education /empowerment programs/classes and provide it to family and friends
  - Provide health information and education with illustration
  - Share real examples through classes
  - Network between clinic and community
  - Train the trainer; provide classes in the community
  - Integrate cooking, exercise, and stress management classes
  - Provide a referral system to podiatrist, ophthalmologist and dentist

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Important Results

- **Positive short-term changes in numerous indicators.**
- **Increase in participants' self-care behaviors, knowledge related to hypertension, and self-efficacy, and decrease in negative impact of stress on health.**
- **The clinical indices of A1C and systolic blood pressure showed a significant decrease before after the HELP sessions.**
- **The groups remained motivated throughout a 9-week intervention; this speaks positively of the engaging and participatory nature of the program.**
- **Qualitative data from implementation staff, facility administrators, and local hub members confirmed participant receptivity to the program and the CHWs' role in facilitating improved knowledge and behavioral changes.**

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Discussion

- Successes
- Challenges and Limitations
- Lessons Learned
- Recommendations and Next Steps

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Pilot Successes

Improvement of self-management practices and positive short term outcomes:
The role of CHW and patient navigators helped to successfully translate the intervention to these minority groups.

Successful Stories:
- One patient quit drinking, one patient quit smoking,
- One patient was a cook at the church, started cooking healthier meals to over 200 parishioners and teaching them to eat healthy.
- For one patient, the physician reduced her medication.
- 14 patients wanted to be trained to teach and train others and disseminate healthy information

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PCCC Overall Success

The successes are multiple despite all the challenges and limitations that PCCC faced from 2010-2013

- ✓ **Commitment to the project and effective stakeholder engagement** was shown by the flexibility of the local hub members and other PCCC team to be receptive to changes
- ✓ **The evidence of shared decision making and engagement** was shown by the establishment of multiple PCCC entities and their continued excellent attendance especially PCCC team leaders, steering committee members, local hubs, and some local workgroup leaders as well.
- ✓ **The capacity building efforts** were successful due to three factors:
  (1) Good reviews given anecdotally to the PCCC team,
  (2) Good attendance, and
  (3) Their application of the skills to complete PCCC tasks.

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Challenges

- **Logistic Aspects: Delay in OMB approval lead to challenges in:**
  - Sustaining stakeholder engagement.
  - Staffing transitions
  - Changes in clinical partners.
  - Short time frame of the program implementation, couldn't assess long term outcome impact
- **Challenges addressing stakeholder demands in the context of Community Participatory Research**
- **Limited resources and funding challenges**
- **Low health literacy**

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Limitations

- Generalizability
- Short time period
- Limited data:
  - Small sample size
  - No control group

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Lessons Learned- Chicago Hub

- Plan effectively: funding for sustainability and flexibility for changes
- Explore other methodological approaches to address low health literacy
- Conduct Participatory Research for dissemination and assistance for the clinics to institutionalize and embed the program within their systems
- Assess the culture of the clinic and the changes needed to accept the value of the CHW
- Examine available clinic and community resources and potential accessibility to referrals for those not available; for example, professional services (podiatrist, ophthalmologist, dentist), space for cooking, exercise and stress management, etc.

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Recommendations and Next steps

- Conduct the interventions on a larger scale and use the original 6-month period for their implementation.
- Implement a comparative effectiveness study to assess the likelihood of replication of the interventions in other geographic areas. Thus, we can gain insight into geographic contexts that may influence study outcomes.
- Implement a study to assess the effects of the intervention on provider and patient/consumer adoption of the new health self-management practices.

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Conclusions

- **Community health workers are an important community resource in addressing low health literacy and health disparities;**
- **Positive short-term changes in biomedical indicators (A1C, systolic blood pressure), self-care behaviors and quality of life;**
- **HELP is an educational tool that can be easily implemented and incorporated in the regular clinical care of patients with chronic conditions;**
- **It is important to engage in and sustain long-term partnerships and relationships in the community;**
- **Leverage resources already available in the community;**
- **Further comparative effectiveness research is needed to validate the results of this pilot.**

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THANK YOU