SYMPOSIUM
Ongoing Support for Health: Impacts of “organizational home” on sustainability of peer support programs

Renée I Boothroyd, Monika Safford,
Guadalupe X. Ayala, John Elder, Ed Fisher

April 13, 2012

Introduction & Overview

Renée I Boothroyd, PhD • boothroy@email.unc.edu
Acknowledgments

Colleagues and our broader Learning Community . . .

- Ed Fisher, PhD, Global Director of Peers for Progress
- Principal Investigators and Collaborative Teams at Peers for Progress Grantee Sites and, more broadly, across Global Network of Peer Support Organizations
- Peers for Progress Team Members and Faculty Advisors at University of North Carolina at Chapel Hill (UNC-CH) and the American Academy of Family Physicians Foundation

boothroy@email.unc.edu
Outline

• Introduce peer support and its contribution to health
• Frame organizational features of context that influence fit, scaling-up, and sustainability of peer support programs
• In the context of Peers for Progress, describe organizational-home case studies of peer support programs
• Examine strengths and challenges of peer support in the context of community and clinical organizations and systems
Complexity of Chronic Disease Management

• Chronic diseases such as diabetes affect all aspects of people’s lives, all the time, for the rest of their lives.

• [Sustained] behavior change is influenced by dynamic and evolving “real-world” conditions.
  – Medical treatment is critical - but often not enough for people to master and maintain the kinds of everyday behaviors that enable them to live as healthily as possible.
  – Improving self-management will have far greater impact on population health than any improvement in specific medical treatment (WHO, 2003)
What and Why: Support

• Ongoing follow-up and support are critical to behavior change
  – Self management & metabolic control: the only predictor of success was the length of time over which contact was maintained (Norris et al., Diabetes Care 2002 25: 1159-1171.)
  – Smoking: success associated with personal assistance repeated in different forms by several sources over the longest feasible period (not novel/unusual interventions (Kottke et al., JAMA 1988 259: 2882-2889; Fiore et al. Treating tobacco use and dependence. USDHHS, 2000) (AHRQ meta-analysis)

• Even with 6 hours per year with a doctor, that leaves over 8000 hours per year “on-your-own” to manage complex behaviors for staying healthy

www.peersforprogress.org
Case for Social & Peer Support

Self-management = Point of Care + Beyond!

With 8760+ hours “on their own” annually, people need

➢ Help figuring out what changes and strategies might work in her/his daily life

➢ Skills to put these things into practice

➢ Ongoing encouragement and support – for day-to-day needs and when things change

➢ Community linkages and resources

➢ Help tying this all together with good clinical care

The Diabetes Educator 2007 33(Suppl 6): 216S-224S

Peer Support
Peers For Progress

Responsive both to the need for/promise of peer support and need for further research

(Boothroyd & Fisher, Family Practice 2010 27 Supp 1: i62-68)

Mission: Accelerate and promote best practices in peer support as a regular part of health, health care, and prevention around the world

Doing so requires attention to
- Evidence and evaluation (research and practice)
- Global networking (identify and exchange models, tools, materials)
- Advocacy and promotion
PEER SUPPORT APPROACH

No “One-size-fits-all”

Peer Advisors in rural areas providing practical and social support via phone

Promotoras help people navigate clinic, family, and community environments

“Lady Health Workers – part of government infrastructure – provide 1:1 support to women in rural villages

“Buddy” dyads among women connect to each other and clinics via group support, mobile phone probes, and texting
Peer Support: Key Functions

1. Assistance, consultation in applying management plans in daily life

2. Social and Emotional Support
   a) Encouragement of use of skills, problem solving
   b) Personal relationships
   c) Social networks and community resources

3. Linkage to clinical care
   a) 2-way relationship between peer program and providers
   b) Peers encourage use of clinical care
   c) Advocacy for enhanced clinical care (and other community resources)

4. Ongoing support, extended over time
   a) Proactive contact and ad lib access to peers
   b) Negotiated plan for support
   c) Variable frequency/intensity over time as needs of recipients change, evolve
So What?

✓ Common functions guide [ongoing] program development for functional coherence across projects

Standardization

Relevance/Fit

✓ Common functions offer a framework for adaptation, local direction, ingenuity, and flexibility
Opportunities for Providers

- Integrate peer support as a powerful outreach and engagement strategy for enhanced systems to care (e.g., Community Oriented Primary Care and Patient Centered Medical Home (PCMH) activities)
  - Culturally sensitive outreach and follow-up
  - Enhanced access to and team-based care
  - Coaching patients to assume more active roles in health care
  - Enhanced communication between patients and providers
Issues/Challenges

- Practical (e.g., financial and human resources in this economy, impacts on recruitment, retention)
- Organizational (e.g., logistics for organizational partnerships, capacities among others, acceptance of “expanded” care teams, payment/reimbursement)
- Programmatic
  - Quality control (content and process)
  - Availability and innovative use of technologies among lower- and higher resourced settings
  - Cultural issues (e.g., relationships with health care providers; lack of physician buy-in regarding need for active patient participation in ongoing management)
Peer coaches and participants part of safety-net clinics in San Francisco, CA area

Coaches intended to be part of clinic teams – *promote shared communication of treatment plans? Coordinate support around appts? Integrate with clinic structure?*

Yet most interactions ended up being by phone or in community settings . . .
Care Companions

- Primary care, physician-centric group of 30 clinics in TX and FL; Medicare/Senior population; 15 practices in project
- Care Companions (mentors) identified from patient pool, trained, engage in clinic-based group sessions with patients
- In clinic setting, not “medicalize” support, but make it fun, social, “fiesta” (not another health care visit)
- Medical care vs. empowerment mindset of staff → Nurse training
- “Activated patient” meant more engagement (aka questions) → Provider training to anticipate and handle that
## Dimensions of Peer Support Programs: Sample Considerations for Program Development & Sustainability

<table>
<thead>
<tr>
<th>Community action and organization approach</th>
<th>Individual, direct service approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community-based</td>
<td>Clinic-based</td>
</tr>
<tr>
<td>Under resourced community and modest health system</td>
<td>Highly resourced community and extensive health system</td>
</tr>
</tbody>
</table>

* Excerpted feedback from Peers for Progress Global Peer Support Research Meeting with 60+ participants from 20+ countries in Kuala Lumpur, Malaysia, October 2010
Some interesting questions . . .

For any organization, systems, infrastructure . . .

- Key features of organizational culture, readiness?
- Champion? [relevant] Leadership? Staff oversight?
- Demonstrating [relevant] value (on the front end and regular, recurrent feedback loops that provide information deemed important by stakeholders)
- Opportunities to fit/integrate with existing infrastructure, procedures, programs – in ways that make sense and are of value to stakeholders?
Outline *Revisited*

**Key Overview Ideas:**

(i) peer support can attend to needs for ongoing support for behavior change; (ii) common functions of peer support facilitate both coherence and adaptation across global context; and (iii) across contexts, organizations offer both strengths and challenges for delivering and sustaining peer support programs.

- Organizational-home case studies of peer support:
  - Monika Safford, ENCOURAGE in rural Alabama
  - Guadalupe X. “Suchi” Ayala, PUENTES in Imperial County, California
- John Elder and Ed Fisher (Discussants) - Examine strengths and challenges of peer support in the context of community and clinical organizations.
IMPLEMENTING A VOLUNTEER PEER SUPPORT TRIAL IN RURAL ALABAMA IN COLLABORATION WITH LOCAL PRIMARY CARE PRACTICES

Monika M. Safford, MD
Principal Investigator
Associate Professor of Medicine
Assistant Dean for Continuing Medical Education
University of Alabama School of Medicine
Disclosures

- Dr. Safford receives salary support for the conduct of investigator-initiated research from:
  - National Institutes of Health
  - Agency for Healthcare Research and Quality
  - Amgen Corporation
  - Pfizer, Inc.

- Encourage was funded by:
  - Peers for Progress, a collaboration between the American Academy of Family Physicians Foundation and the Eli Lilly Foundation
  - University of Alabama at Birmingham Diabetes Research and Training Center (funded by NIDDK)
Outline

- Setting
- Plans
- Barriers
- Solutions/Work-Arounds
- Repercussions
- Next steps
The Setting

- **Southeastern US:**
  - Highest stroke and coronary heart disease mortality
  - High burden of diabetes

- **Rural southeastern US:**
  - High poverty (~30% in black communities)
  - Scarce resources (2 certified diabetes educators for 8 counties)
The Black Belt

- Booker T. Washington:

  The term was first used to designate a part of the country which was distinguished by the color of the soil. The part of the country possessing this thick, dark, and naturally rich soil was, of course, the part of the South where the slaves were most profitable, and consequently they were taken there in the largest numbers. Later and especially since the war, the term seems to be used wholly in a political sense—that is, to designate the counties where the black people outnumber the white.
The Black Belt

- Booker T. Washington:
  The term was first used to designate a part of the country which was distinguished by the color of the soil. The part of the country possessing this thick, dark, and naturally rich soil was, of course, the part of the South where the slaves were most profitable, and consequently they were taken there in the largest numbers. Later and especially since the war, the term seems to be used wholly in a political sense—that is, to designate the counties where the black people outnumber the white.
The Black Belt

- Booker T. Washington:

  The term was first used to designate a part of the country which was distinguished by the color of the soil. The part of the country possessing this thick, dark, and naturally rich soil was, of course, the part of the South where the slaves were most profitable, and consequently they were taken there in the largest numbers. Later and especially since the war, the term seems to be used wholly in a political sense—that is, to designate the counties where the black people outnumber the white.
3 Community-based teams:
- Community Coordinator
  + Assistant
- Peer supporters
- Interviewers
- Recruiters
3 Community-based teams:
- Community Coordinator + Assistant
- Peer supporters
- Interviewers
- Recruiters

[Map showing the Western Black Belt region]
3 Community-based teams:

- Community Coordinator
  + Assistant
- Peer supporters
- Interviewers
- Recruiters
3 Community-based teams:
- Community Coordinator + Assistant
- Peer supporters
- Interviewers
- Recruiters

Western Black Belt

Central Black Belt

Southern Black Belt
The Setting: Rural Alabama Medicine

- Low HMO penetration (90% fee-for-service)
- Black Belt:
  - “Large” 2-5 MD/NP
  - Single MD/NP, trailer
  - Some FQHCs – large, small
  - MD shortage: e.g., Wilcox County: 2 MD’s
    - Not unusual: 50 miles one way
  - Health Professionals Shortage Area
    - Asian Indian doctors
The Setting: Central Black Belt

Marion Health Center
One Indian MD

Folklore: Haint Blue
The Setting: Southern Black Belt

Sisters of St. Joseph’s, NP and MD

Pine Apple Town Hall
The Setting: Western Black Belt
The Encourage Trial

Is education + volunteer peer coaching more effective in improving diabetes outcomes than education alone?
Intervention

- Volunteer peer coaches
  - Have diabetes or help a friend/family member with diabetes self-care
  - 2-day training: diabetes basics, motivational interviewing skills, principles of research, protocol
- Get-to-know you face-to-face meeting
- Weekly telephone conversation x 8-12 weeks
- Monthly thereafter for total of one year
- Call before and after healthcare provider visit
The Plan

- Work with 12 community primary care practices
- Recruit through practices
- Link clients into clinical care
- Introduce peer coaching to rural Alabama primary care practices
- Sustainability
The Plan: 400 ppts w/ A1c >8%

- Large practices (n=6)
  - 500+ patients/week
  - 30-50% diabetes patients, 50% A1c > 8.0%
  - Goal: **12-15 referrals/wk** (practice estimate: 20-30)

- Small practices (n=6)
  - 40-100 patients/week
  - Goal: **2-5 referrals/wk** (practice estimate: 8-10)

- **Total: 100-120/wk**
The Reality: So far so good

- Lunch meetings with each practice
- Practice champion identified
- Recruitment strategies adapted for each practice
  - Lists of patients w/ A1c >8%
  - Research staff to call
  - Station research staff in waiting room
- Uniformly high enthusiasm and support
  - Thought recruitment pace too modest
The Reality: Not so good

- IRB
  - Research staff cannot contact patients without patient signed approval to do so (HIPAA)
  - Practice staff would need to obtain signatures
The Reality: Not so good

- Actual recruitment pace at 3 months:
  - 30 patients referred
Barriers

- No time
- Forgetting
- Too busy
- Misplacing study materials
- Research staff turnover, lapses in contacts
- Some community coordinators not familiar with practice staff, shy
- MD says yes, corporation says no
Solutions/Work-Arounds

- Expand recruitment strategy
  - Community coordinator social networks
  - Community recruiters
    - $5 /eligible ppt for screening
  - Accept eligible walk-ins on recruitment day
  - Research staff networks
Sources of Participants


*Note: The total number of individuals who walked in was not tracked; only the total number of walk-ins that were enrolled was tracked.*
Sources of Participants

*Note: The total number of individuals who walked in was not tracked; only the total number of walk-ins that were enrolled was tracked.

Consequences

- No longer linked to practices
  - Total practices = 110 (!)

- Group randomization scheme?
  - One practice/community
  - Practice randomization → community randomization

- Relax A1c inclusion criterion
  - Not feasible: turn away community members who want help with diabetes, A1c ≤ 8%
Consequences

- Original plan: practice-based intervention
- Reality: community-based intervention
- Practices did not gain familiarity with peer coaching
- Linkage to clinical care was entirely driven by peer-client dyad
- Sustainability?
Unintended Consequences

- Higher visibility in partnering communities
- Involvement of community businesses, organizations ("natural coalition")
- High enthusiasm among peers
- Empowerment for capacity building: one community coordinator nonprofit as an organizational home for peer support programs?
Next Steps

- Practice debriefing in process
- Next study (AHRQ R18)
  - Community coordinators who are well-known to practices – regular visits
  - Engage more practices (Encourage initial n=12, final number of practices=110)
    - No expectation of practice-based recruitment
  - Free CME program on community health workers for diabetes for MDs, NPs, RNs
  - Branding: structured forms with study logo
Next Steps

- Hire community health workers through community-based organization
  - Western Black Belt community coordinator’s nonprofit
  - Southern Black Belt community coordinator as a satellite
  - Subcontract with University
  - Capacity building, sustainability
  - ACA (??)
The Encourage Team

- Monika Safford, MD, PI
- Andrea Cherrington, MD, Co-PI
- Jewell Halanych, MD; Michelle Martin, PhD; Annette Wright, RN, PhD
- Susan Andreae, Lynn Andreae, Marquita Lewis
- Debra Clark, Ethel Johnson, Sheree Stallworth
- Our peer volunteers
- Our participants
- Numerous Black Belt community businesses and groups who supported the study through donations of space, time and enthusiasm
Questions?
Working with a federally qualified health center to implement a volunteer peer support program

Guadalupe X. Ayala, PhD, MPH
Professor, San Diego State University
Co-Director, San Diego Prevention Research Center
Senior Core Investigator, Institute for Behavioral & Community Health
Study Overview

• Test a peer support intervention to improve glycemic control among rural low-income Mexican immigrants/Mexican-Americans living in Imperial County, CA.

• Peer supporters (líderes; leaders) identified from Clinicas de Salud del Pueblo, Inc., a federally-qualified health center.

• Patients (compañeros) randomly sampled from CDSDP patient roster.

• Primary outcome is HbA1c, quality of life, depression, self-management.
Imperial County, California, USA

- 166,874 residents
- 77% are Mexican origin
- 67% speak other than English
- 41% did not complete high school
- Median HH income $33,576
- 22% live below poverty level

Darker = more economically stressed

www.peersforprogress.org
Diabetes in the U.S. Latino community

2004-06 BRFSS data

Prevalence of diabetes

- Non-Hispanics
- Hispanics
- Cubans
- Mexican-Americans
- Puerto-Ricans

2004-06 BRFSS data
Clinic partner

• Federally qualified health center
• Serves Imperial County and Southeast Riverside County
• Largest provider of primary health care in these regions
• 10 clinic sites and 1 administrative office
Clinicas de Salud del Pueblo, Inc.

11 departments
340 employees

15 Board of Directors:
51% consumer members
49% professional members
Community Health Outreach Department

- More than 15 years experience in outreach, education, referral, case-management and advocacy
- Address emerging issues
- Paid staff, some volunteers
- Grant funded
Study phases

1. Decide on program structure
2. Develop curriculum
3. Train peer leaders and inform providers
4. Evaluate implementation
5. Assess potential to sustain
Decide on program structure

- **Assumption 1:** Peer leaders are not community health workers
  - Not credible
  - Not valued
  - Not worthy of system integration

- **Assumption 2:** Limited potential with volunteers
  - Cannot expect much
  - High risk for dropout
Program structure - Leaders

- Identify peer leaders through providers and outreach department staff
- Screen and enroll leaders ($\approx 10$ per clinic)
- Train leaders to provide one-on-one or group based support (including HIPAA and IRB compliant)
- Assign each leader to work with 6 patients
- Monitor and support peer leader activities
Program structure - Clinics

• Introduce program to clinic staff

• Inform providers of patient involvement, including medical chart note

• Create opportunities for leaders and providers to meet
Develop curriculum for leaders

1. Introduction to *Puente*
2. Introduction to peer support
3. Diabetes & nutrition
4. Diabetes & physical activity
5. Diabetes & emotional health
6. Medical mgmt. of diabetes
7. Conducting home visits
8. Conducting visits to the clinic
9. Conducting support groups
10. Monitoring your support

- 40 hours of training
- Focus on modalities of support
- NOT educators
Conducting visits to the clinic

Visit to the clinic #2

Here is a suggested second visit to the clinic.

1) Introduce the topic of communication and how to stay on top of your medications and how overwhelmed you may feel during your visits and how doctors and nurses can help you.

PREPARE FOR THE VISIT

- Make a list of questions for your providers.
- Bring a list of your medications and doses.
- Bring a friend or relative if you need someone to help with remembering the information.

DURING THE VISIT

- Share both the good and bad with your provider. For example, explain any symptoms and problems you are experiencing.
- Share information about other forms of treatment, such as taking vitamins or eating cactus leaves that you know.
- Tell your doctor how your medications are working.
- Ask your health care provider to write in your medical record what was discussed.
- Ask to see any test results and request a follow-up appointment.

Role play

CHARACTERS

Patient: The patient is a 45-year-old man who was diagnosed with diabetes about 5 years ago. He has a family history of diabetes so he was not that surprised by the diagnosis. However, he was surprised by how much work it takes to manage this disease. He has been skeptical about this because he does not remember his aunts in Mexico going to the doctor so often, and they never changed their lifestyle. Now he is at the clinic because his most recent blood glucose test indicated that he was hyperglycemic.

Doctor: The doctor has been working at the clinic for over 20 years and knows this patient pretty well. She is a little frustrated by the patient’s attitude toward his disease and his lack of effort to change his lifestyle to control his diabetes.

SITUATIONS TO ADDRESS IN THE ROLE PLAY

First, pretend like the interaction turned out very poorly. What might have happened to make it go so bad—think both from the perspective of the patient and the doctor? What could have been done differently?

Second, pretend like the interaction turned out very well. What techniques did the doctor use to engage the patient? What did the patient do to appear more receptive to the doctor and her advice?

Build your skills | Partner with a fellow leader and role play this activity, with one person acting as the peer and one person acting as the doctor. After the role play, write down how you felt in your role. Be prepared to share your experiences with others.
They also want to stress to you, as leaders, to know your limits... and know when to report any red flags to your coordinator.
<table>
<thead>
<tr>
<th>Peer Leaders</th>
<th>N=34</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average age (SD)</td>
<td>44 (9)</td>
</tr>
<tr>
<td>Female</td>
<td>97% (33)</td>
</tr>
<tr>
<td>Foreign born (in Mexico)</td>
<td>82% (28)</td>
</tr>
<tr>
<td>Married or living as married</td>
<td>79% (27)</td>
</tr>
<tr>
<td>Employed full or part-time</td>
<td>53% (18)</td>
</tr>
<tr>
<td>High school educated</td>
<td>59% (20)</td>
</tr>
<tr>
<td>Other volunteer activities</td>
<td>38% (13)</td>
</tr>
</tbody>
</table>
Unanticipated outcomes

• Concurrent changes in health care system
  – More diabetes services – did leaders increase demand?

• Providers more receptive to working with community health workers
  – Member of team – did leaders demonstrate their value?
Patient’s perspective

Helped you get care?

- Not at all: 10%
- A little: 20%
- A moderate amount: 15%
- A great deal: 55%

Helped you with doctor/nurse?

- Not at all: 20%
- A little: 15%
- A moderate amount: 30%
- A great deal: 35%
Lessons learned

• Start slowly if necessary and be patient.

• Modify attributions made.

• Don’t give up.
Acknowledgements

Co-Investigators
Leticia Ibarra, MPH
SDSURF

John P. Elder, PhD, MPH
San Diego State University

Ming Ji, PhD
San Diego State University

Andrea Cherrington, MD, MPH,
University of Alabama at Birmingham

Mark Snyder, PhD
University of Minnesota

Staff
Lucy Horton, MPH, MS, Project Mgr.
Humberto Parada, MPH, Data Mgr.

Maria Belen Luna, Coordinator
Cecilia Cota, Diabetes education

Funder
Peers for Progress
American Academy of Family Physicians
SOOOIII24OIGEL (02/01/09-09/30/11)
Thank you!

¡Gracias!
Impact of “organizational home” on sustainability of peer support programs: A few comments

John Elder, PhD, MPH

San Diego State University
Co-Investigator, Peers for Progress-Imperial County (CA)
Peer-led interventions:

• Show substantial potential for controlling chronic disease
• Improve investigators’ ability to retain participants in studies for long-term follow-up
• Can attract motivated and enthusiastic volunteers
• May improve reach, visibility and PR of primary care organization
But what about cost-effectiveness?

• A primary care physician with a panel of 2500 patients would spend:
  – 7.4 hours per day to deliver all recommended preventive care (Knox presentation)
  – 10.6 hours per day for chronic care

• BUT
  – Peer leaders require substantial ‘care and feeding’, material support, and replacement
  – Volunteer coordinators have to be added to payroll
  – Resistance from primary care staff to integrating volunteers and promotoras into primary care team
Three group, randomized experiment

351 participants, randomly assigned to

- Off-the-shelf print
- Targeted and tailored print
- Targeted and tailored print + promotora/face to face communication
Promotora Experience: ‘Secretos de la Buena Vida’

- Impact was generally greater in *promotora* group
- Mailing, supplies and personnel costs for usual care = $9 per participant.
- per participant cost = $45 for the tailored print-only condition.
- *Promotora*- related expenses, especially mileage reimbursement, raised the cost of this approach to slightly more than $135 per participant
- Costs per reduced gram of dietary fat were $1.30, $5.11 and $8.28.
And Are We Promoting Health Equity?

• Peer-led interventions increase access to primary care and promote patient adherence
• MD shortage in underserved areas: e.g., Wilcox County (AL): 2 MD’s; 50 mile drives to clinics being common
• coverage is often provided by professionals who aren’t well acquainted with a culture or language, e.g. Asian immigrant doctors in much of the Southeast; Anglo/English-only doctors in the Southwest
But..............

• Do we reduce health disparities with peer, auxiliary and promotoral-lead programs OR do we institutionalize them?
• In other words are peer led programs permanent answers, or band-aids until affordable “high quality” health care is available?
• Do we add stress to the clinic’s stretched resources and its professional environment?
Empirical Challenges
Since “one size does [not] fit all”…..

• Can we really learn from one another’s experiences between cultures and nations, or even between clinics within regions, and regions within a nation?
• If we cannot standardize interventions, how can we standardize measures in a way that produces interpretable outcomes?
• How do social desirability and other threats to validity play out across cultures?
• To what extent does the organizational environment predict peer success, and how do we measure that?
Are we measuring the correct outcomes?

• Is quality of life better manifested through emotional well being (less depression, diabetes distress) than physical/physiological indices?

• What changes in the peers themselves, the patients’ social networks, clinics/health care organizations and their communities are evidenced?

• Are we underselling impact of peer-led interventions?