



TRANSLATING SELF-MANAGEMENT STRATEGIES IN COMMUNITY SETTINGS

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Overview

- Present overview of self-management (SM) programs and outcome data
 - ▣ Describe knowledge gaps
- Present four studies involving translation of SM programs in community settings
- Highlight importance/relevance of work by co-presenters Drs. Brady, Schlenk & Rini
- Summarize research/policy issues

Self-Management Definition

- What individuals do to manage, adjust to, & minimize impact of chronic condition(s) in context of daily life
- Multiple challenges:
 - ▣ Integrating treatment/management approaches for disease and disease-related complications
 - ▣ Maintaining meaningful life roles in face of disease sequelae
 - ▣ Dealing with emotional sequelae that occur as consequence

Self-Management Education

- Programs/initiatives to help affected individuals:
 - ▣ Optimally manage a given chronic condition or conditions
 - ▣ Minimize short and long-term health consequences
 - ▣ Achieve best quality of life possible

Self-Management Support

- Things that other individuals do (e.g., healthcare professionals, family members, informal caregivers) to support individual's self-management activities
 - Engagement
 - Maintenance
 - Relapse

Focus on Self-Management

- PubMed search for 'self-management' in title, abstract or text
 - 1965 30
 - 1985 984
 - Past year $\approx 10,000$

What's Driving The Interest?

- High prevalence of chronic disease:¹
 - ▣ Ages 45-65: 20% have ≥ 2 chronic conditions;
 - ▣ Ages >65 : 45% have 2 or more chronic conditions
 - ▣ Associated morbidity & suffering
- Economic burden: 78% of all health care spending; 96% of Medicare expenditures
- Current healthcare model ineffective

¹ <http://www.cdc.gov/nchs/data/databriefs/db100.pdf>

Self-Management Programs

- ❑ Arthritis Self-Management Program (Spanish language version available)
- ❑ Back Pain Self-Management Program
- ❑ Chronic Pain Self-Management Program
- ❑ I'm Taking Charge of My Arthritis
- ❑ Manage Your Pain
- ❑ Chronic Disease Self-Management Program (Spanish language version available)



Self-Management Programs Targeting Other Chronic Diseases

- ❑ Diabetes
- ❑ Heart disease
- ❑ Obesity
- ❑ Asthma/COPD
- ❑ Stroke
- ❑ Chronic kidney disease
- ❑ HIV
- ❑ Peripheral arterial disease



Core Self-Management Skills

- **Problem solving:** Skills to solve everyday problems arising as consequence of illness
- **Decision making:** Ability to make sound decisions regarding chronic disease management
- **Resource utilization:** How to access available resources
- **Partnership formation:** How to build & maintain partnerships to best address illness
- **Taking action:** How to set & achieve goals (via action plans)

Social Cognitive Theory

- Self-efficacy enhancement
 - ▣ **Skills mastery**: Goal setting, action planning, and problem solving
 - ▣ **Modeling**: Having peers teach and demonstrate self-management principles
 - ▣ **Social persuasion**: Group participation reinforces engagement and uptake of self-management practices

Typical Intervention Elements (ASMP)

- Group based (up to 15 participants)
- 2 to 2.5 hour classes once a week
- Six week duration
- Trained instructors (e.g., peer-led, health professional)

Key Intervention Elements (ASMP)

- Education about arthritis and its consequences
- Relaxation skills training
- Cognitive coping skills training
- Problem solving
- Communication skills training
- Weekly action plans

ASMP Topics Covered Weekly

Topic	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6
Self-management principles	√					
Cognitive pain management	√		√	√	√	
Goal setting/action plans	√	√	√	√	√	√
Problem solving		√	√	√	√	√
Handling difficult emotions			√			
Address importance of exercise		√	√	√		

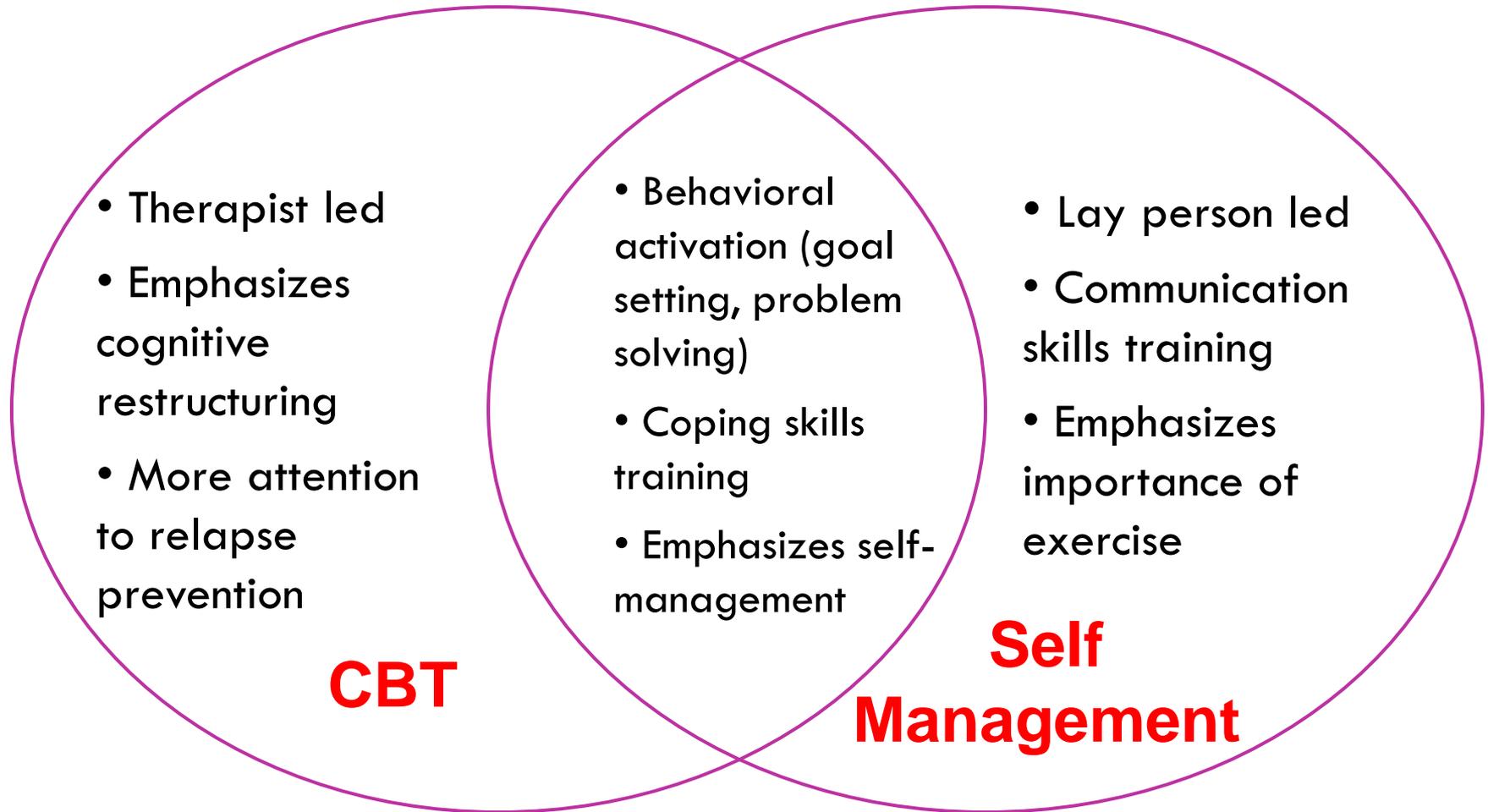
Implementation Sites

- Community centers
- Faith-based organizations
- Schools
- Work places
- Healthcare institutions

Is Self-Management Different than Cognitive-Behavioral Therapy?

- Help patients understand how specific cognitions & behaviors negatively affect pain experience
- Provide coping skills training (e.g., relaxation, activity pacing, pleasant activity scheduling)
- Emphasize role patients can play in managing their pain and pain-related behaviors
- Provide opportunities for application & maintenance of learned skills (action plans, problem solving)

CBT Versus Self-Management Programs



Are Self-Management Programs Effective?

- At least 5 systematic reviews/meta-analyses:
 - ▣ Arthritis, chronic musculoskeletal conditions, or chronic disease (with arthritis as primary contributor)
 - ▣ Combined diverse self-management programs (mostly ASMP and CDSMP)
- Study periods spanned 45+ yr period: (1964-2010)
- 90% of studies/evaluations took place in community settings

(1) Warsi et al. *Arth Rheum* 2003;48:2207-13; (2) Nunez et al. *World Evidence-Based Nurs* 2009;6:130-48. (3) Du et al. *Pat Educ Coun* 2011;85:e299-310. (4) Nolte & Osborne. *Qual Life Res* 2012 Oct 31. [Epub ahead of print]; (5) Foster et al. *Cochrane Review* 2009.

Results of Meta-Analyses

- Small effect sizes:
 - Pain
 - Self-reported disability
 - Mood
 - Associated symptoms (fatigue)
- Moderate effect sizes:
 - Cognitive symptom management
 - Exercise behaviors
 - Self-efficacy enhancement
- Large effect sizes: Knowledge gained

Measuring Right Outcomes?

- Osborne & colleagues developed Health Education Impact Questionnaire¹
- Used concept mapping process gathering data from
 - ▣ Individuals with chronic diseases
 - ▣ Healthcare professionals
- Generated 42-item instrument with 8 core domains

¹Osborne et al. Pat Educ Couns. 2007;66:192-211.

Self-Management Program Effects¹

Domain	% with Substantial Benefit ²
Positive and active engagement in life	37%
Health directed behavior	35%
Skills acquisition	49%
Constructive attitudes/insight	32%
Self-monitoring skills	32%
Health services navigation	27%
Social support	32%
Emotional well being	34%

¹Results generated from 142 CDSMP course offerings (N=1,341). ² Substantial benefit defined as estimated ES \geq 0.50.

Groups Endorsing Approach

- CDC/Arthritis Foundation: National Public Health Agenda for Osteoarthritis (2011) ten key recommendations:
 - Self-management education should be expanded as community-based intervention
- IOM's Report on Pain (2011):
 - Promote and enable self-management of pain
 - Key emphasis on healthcare organizations and role healthcare providers could play

Self Management in the Medical Home



- Feasible only when patients take active role in care
- Empowering patients with self-management tools critical to medical home model success
- Use of self-management tools help clinicians and healthcare organizations meet NCQA requirements for medical home certification

Knowledge Gaps

- Generalizability issues: Evaluations/studies conducted using largely non-Hispanic white populations
 - ▣ Limited reach particularly in minority communities¹
- Problems with program attrition 10-50% average \approx 25%¹
- Problems sustaining programs at organizational or agency level²
- Problems maintaining treatment effects at individual level³

¹Rizzo et al. 2007. Report New York State Chapter of the Arthritis Foundation; ¹Warsi et al. Arth Rheum 2003;48:2207-13; ²Townley et al. Pain Med. 2010;11:405-15; ³Goeppinger et al. Arth Rheum 2007;57:1081-88; ³LaForest et al. Can J Aging 2012;31:195-207.

Translating Self-Management Strategies in Community Settings



Translating Self-Management Strategies in Community Settings (Study 1)

- Research question: Can program adaptation lead to improved outcomes in minority populations?
- Partners (in studies 1-3):
 - ▣ New York City Chapter of Arthritis Foundation
 - ▣ New York City Council of Senior Center Services
- Target implementation site = senior centers
 - ▣ 15 million seniors access services provided by more than 15,000 centers nationwide
 - ▣ 300+ centers throughout all 5 NYC boroughs

Methods (Study 1)

- Evidence based program = ASMP
 - ▣ Implemented English-language version in centers serving African American and non-Hispanic whites ; Spanish-language version in centers serving Hispanic adults
- Adaptation approach:
 - ▣ Employed Community Based Participatory Research
 - ▣ Implemented program in 3 senior centers (each serving homogeneous group: African American, Hispanic, non-Hispanic White) 3 times each = 9 program courses
 - ▣ Participants = Age 60+ with self-reported arthritis conditions
 - Phoned weekly to identify likes, dislikes, suggestions for programmatic change

Methods (Study 1)

- ▣ Convened participant focus groups after 6th (final) session
 - Presented findings from weekly phone calls
 - Participants voted on recommendations
 - Solicited additional ideas for programmatic change
- ▣ Above process duplicated for ASMP course leaders

Results (Study 1)

- ASMP participants provided 71 unique recommendations for program change
 - ▣ 27% content additions
 - ▣ 32% augmentations to class program and/or materials
 - ▣ 41% changes in program delivery
- Program instructors made 15 recommendations (5 of which were also made by program participants)

Results (Study 1)

- Project's Community Advisory Board adjudicated recommended changes
 - ▣ Multiple constituencies: ASMP content expert, AF staff, senior center directors/staff, seniors with pain, & researchers
 - ▣ Reviewed each proposed change:
 - Importance
 - Feasibility
 - Congruence (with core ASMP components)
 - ▣ Adjudication process took \approx 12 hours to complete
- Method of program adaptation published¹

Examples of Accepted Changes

Accepted Recommendations	Actions Taken by Committee
Content additions	
Add exercise component	Added in-class exercise to English language version (already present in Spanish version)
Add section on spirituality	Added discussion of spirituality and included in list of coping mechanisms
Augmentation of course materials	
Expand section on cognitive techniques/meditation	Added brief meditation component at end of each class
Expand section on healthy eating	Provided hand outs on topic
Expand section on analgesic medication use	Provided handouts on pain meds and safe use recommendations
Alterations in program delivery	
Customize class to client's health literacy level	Added health literacy survey at first class

Conclusion (Study 1)

- CBPR feasible tool for adapting evidence-based programs in community setting
 - ▣ Participants exposed to **all elements of protocol**¹
- Programmatic changes made reflected participants' preferences and needs
 - ▣ Did not alter core components
- Raises question as to whether adapted program would produce equivalent or possibly superior outcomes relative to original?

¹Chen et al. Eval Health Professions 2012;36:73-92.

Translating Self-Management Strategies in Community Settings (Study 2)

- Research question: Does adapted program produce equivalent or superior outcomes?
- Conducted controlled study
- Participants: Ages 60+ with self-reported arthritis conditions
- Setting: 8 NYC senior centers
- Implemented each course (adapted and original) 9 times = 18 separate classes
 - ▣ English version 6 times; Spanish version 3 times

Methods/Results (Study 2)

- Enrolled 201 adults (71% of eligibles)
 - Equal numbers of African Americans, Hispanics, and non-Hispanic whites
- Measured short-term (10 week) and intermediate-term (24 week) outcomes
- Mean age = 74
- Mostly female = 78%
- Over half reported OA as cause of pain (54%)
- Average pain duration \approx 8 years

Results (Study 2)

- Process outcomes (6 class sessions):
 - ▣ Attendance: 4.7 vs. 3.1 $p < 0.01$; $A > O$
 - ▣ Retention: 7% vs. 25% $p < 0.01$; $A > O$
- Both programs produced clinically and statistically significant increases in exercise behaviors and use of cognitive coping skills at 2 and 6 months
 - ▣ 50% increase in days practicing endurance exercises
 - ▣ 65% increase in days practicing stretching exercises
 - ▣ 130% increase in days using relaxation techniques
 - ▣ No differences by race/ethnicity

Results (Study 2)

- Both programs produced clinically and statistically significant increases in efficacy outcomes:
 - ▣ ↓ Pain intensity (23%)
 - ▣ ↑ Mood (18%)
 - ▣ ↓ Perceived disability due to pain (RMDQ) (17%)
 - ▣ ↓ Fatigue (16%) and stiffness (24%)
- No differences by race/ethnicity group

Conclusion (Study 2)

- Translation of original ASMP led to adapted program that:
 - ▣ Maintained benefits in exercise behavior and cognitive coping skills
 - ▣ Produced similar outcomes in key efficacy domains
 - ▣ Improved program attendance & retention
 - **Could help with program reach**

Unanticipated Outcome (Study 2)

- Clients exposed to ASMP at one Harlem center urged staff to form group for continued practice
 - ▣ Clients continue to meet weekly for 2 hours to practice techniques/provide ongoing support
 - ▣ Peer-led program entitled “Beyond the Pain”

Unanticipated Outcome (Study 2)

- ▣ Evaluated “Beyond the Pain” program via CTSC funded grant; positive long-term effects found in:
 - Confidence to do ADLs despite pain
 - Use of exercise and cognitive skills techniques
 - Credit ongoing social support from group
- ▣ Currently working with other senior centers in Harlem to implement BTP
 - Maintain ASMP treatment gains over time?

Translating Self-Management Strategies in Community Settings (Study 3)

- Purpose: Adapt evidence-based pain self-management program for use in home care
 - ▣ Half of all patients receiving home care report activity-limiting pain¹
- Physical therapists ideally positioned to deliver
 - ▣ Frequently care for patients with activity-limiting pain¹
 - ▣ Voice interest in learning self-management techniques for use when treating patients with pain²
- Work conducted in partnership with Visiting Nurse Service of NY

¹Beissner et al. J Geriatr Phys Ther. 2012; Sept 12, epub ahead of print. ²Beissner et al. Phys Ther. 2009;89:456-69.

Methods (Study 3)

- Convened focus groups of PTs working in home care
- Groups reviewed all aspects of 8-session evidence-based SM protocol; made recommendations for program modification
 - ▣ Principal criterion: Feasibility of implementation
- Adaptation committee adjudicated all proposed modifications:
 - ▣ Composed of psychologist, pain expert, physical therapists, experts in home care delivery, & research team

Results (Study 3)

- Six session protocol (delivered in conjunction with customary PT)¹
 - Pain education
 - Goal setting/problem solving
 - Relaxation techniques
 - Cognitive coping skills
 - Behavioral techniques (activity pacing)
 - Relapse prevention
- PTs trained to deliver protocol in home care²
 - Feasibly implemented with high treatment fidelity
 - High patient and PT satisfaction with protocol

¹Beissner et al J Geriatr Phys Ther 2012 Sept 12 epub ahead of print. ²Bach et al. J Geriatr Phys Ther. 2012; Sept 12 epub ahead of print.

Study 4

- Cluster RCT to test effectiveness of protocol (vs. usual care) in home care setting
- Participants: Ages 55+ receiving home care services with activity-limiting pain on admission
- Setting: New York City (all five boroughs)
- Primary outcomes:
 - ▣ Performance-based tests (e.g., timed up and go, timed chair stands)
 - ▣ Pain intensity
 - ▣ Perceived disability due to pain (RMDQ)
 - ▣ Self-reported functional status

Study 4

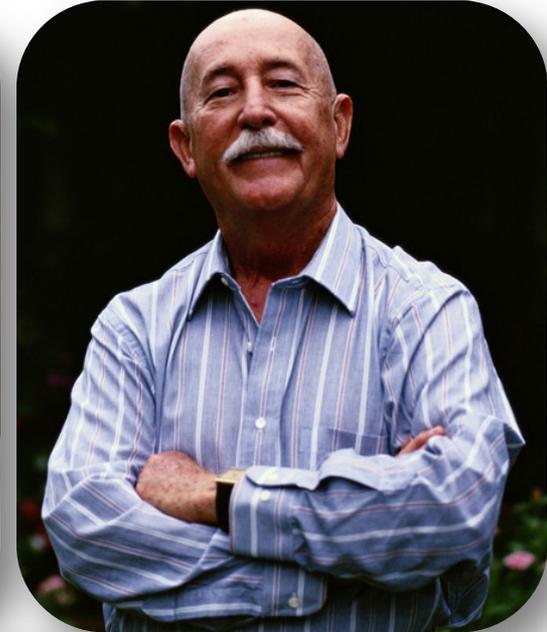
- Adequately powered to test for treatment differences based on patients' baseline characteristics (e.g., PHQ-9 score, baseline self-efficacy, degree of maladaptive coping strategies, race/ethnicity, pain type, etc.)
- Status:
 - ▣ PTs randomized by team; trained half of all teams (20/40) in two 1/2 day training sessions (N≈175)
 - Online video podcasts available for reinforcement
 - Six-month reinforcement sessions completed with all PTs in active intervention arm
 - ▣ Enrolled 280 patients (target N=600)

Take Home Messages Regarding Community-Based Translational Initiatives

- Partnering with community-based agencies provides multiple dividends
 - ▣ Local knowledge
 - ▣ Community-generated ideas regarding how best to improve SM education programs
 - ▣ Excellent collaborators
 - ▣ Access to diverse patient/client populations with high prevalence of pain disorders
- Sustaining self-management programs at agency level remains challenging

Highlight Work by Co-Presenters

- Dr. Teresa Brady
- Dr. Elizabeth Schlenk
- Dr. Christine Rini



Session Co-Presenters

- Dr. Brady: Meta-analysis of Chronic Disease Self-Management Program (CDSMP)
- Dr. Schlenk: RCT designed to increase physical activity in individuals with OA: “Staying Active with Arthritis: An Intervention Guided by Self-Efficacy Theory”
- Dr. Rini: RCT evaluating internet-based Pain Coping Skills intervention for individuals with OA

CDSMP Meta-Analysis

- Timely given recent CDSMP implementation initiatives (e.g., CDC-AOA 2010-2012); and increased federal funding to state agencies to support efforts
- Adequate data to examine both short and long-term program outcomes
- Ability to examine wide range of salient outcomes
- Prior meta-analyses combined results from many SM programs (→large variances)
 - ▣ Current analysis examines results of single program

Staying Active with Arthritis

- Strategies designed to enhance use of exercise in OA populations likely to have significant impact at population level (pay dividends in multiple health domains)
- Multidisciplinary delivery approach (PTs and RNs)
- Reinforcement component via telephone check-ups
- eDiary use for recording outcomes
- Use of actigraphs/acclerometers will generate objective measures of physical activity
- Opportunity to address maladaptive (and prevalent) beliefs about exercise in persons with arthritis¹

¹Holden et al. Arth Care Res 2012;64:1554-64.

Pain Coping Skills Training Intervention

- Pressing need for new program delivery methods
- Online approach offers several advantages
 - Ease of access
 - Scalability
 - Social network opportunities
 - Track time spent on site
- Employs innovative PainCOACH model
- Minimizes text-based information, important for individuals with low health literacy

Summary Research/Policy Issues

- Effect sizes of self-management programs remain in low-to-moderate range
- Efforts needed to augment treatment effects
 - ▣ Will increased intensity or exposure duration help?
 - ▣ Can standard programs be linked with online or mHealth tools that reinforce/augment treatment gains?
 - ▣ Need for tailored SM approaches? (Tailored CBT?)
 - ▣ Target only those individuals with low SM skills?
 - ▣ How can we best leverage individuals' existing social networks?

Summary Research/Policy Issues

- Program maintenance at agency/organization level remains challenging
 - ▣ Need to build capacity to embed program delivery capacity at community agency level
 - ▣ Most senior centers now offer online access and training
 - Online approaches may help but will miss important populations who could benefit
 - ▣ Critical barrier remains lack of funding

Summary Research/Policy Issues

- Maintenance of treatment gains at individual level needs attention
 - ▣ Online and mHealth approaches may help and offer exciting opportunities to
 - To reinforce behavior change via positive feedback
 - Identify trends that indicate decreases in use of specific behaviors
 - ▣ Can peer leaders who implement programs also serve to reinforce treatment gains over time?
 - Role of virtual vs. real-life peer coaches?

Summary Research/Policy Issues

- Bridge gap between community agencies and healthcare systems to improve program reach
- One of strongest predictors of SM program participation is physician referral
 - ▣ Healthcare providers open to possibility of patient referral to community agencies but lack knowledge about programming¹
 - ▣ Demonstrating ability to offer quality programming with associated positive outcomes will help providers²
 - ▣ Building capacity for program delivery in systematic (vs. sporadic) fashion also likely to help²

¹<http://collectiveactionlab.com/sites/default/files/PCP%20Research%20NCHM.PDF>

²Ory M. J Am Geriatr Soc 2013;61:821-3.

Summary Research/Policy Issues

- Build capacity to provide self-management education and support in healthcare system
 - ▣ Require training providers with requisite skills
 - ▣ Low tech nature of approach constitutes barrier
 - ▣ Biggest barrier is inadequate reimbursement

Summary Research/Policy Issues

- Self-management approaches successfully implemented in primary care in **efficacy** studies¹
 - ▣ Successfully delivered by nurse case managers (**S**tepped **C**are for **A**ffective disorders and **M**usculoskeletal **P**ain or SCAMP trial)¹
 - ▣ Moderate to strong effects for pain reduction and pain-related disability
- Large **effectiveness** trial (N=5,599) was negative²
- Efforts needed to determine how best to integrate SM support into primary (and other healthcare) settings

¹Kroenke et al. JAMA 2009;301:2099-10. ²Kennedy et al. BMJ 2013;346: (Published May 13, 2013.)

What Does SM Program Success Look Like to a Geriatrician?



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