The Translational Research Institute on Pain in Later Life (TRIPLL) at Cornell University

- NIA funded Edward R. Roybal center established in response to the plight of millions of older adults experiencing persistent pain.
- Mission: To improve the prevention and management of pain in later life; thereby increasing the health and well-being of older adults.
- Supports translational research on aging and pain in greater NYC area.

Get Involved with TRIPLL

- Email Cara Kenien at cak2017@med.cornell.edu to join our email list and become an affiliate; joining gives you access to:
  - TRIPLL's monthly newsletter.
  - Information about upcoming Work-in-Progress Seminars, webinar and funding announcements, and conference opportunities.
  - Networking opportunities.

Visit http://tripll.org for more information.

TRANSLATING SELF-MANAGEMENT STRATEGIES IN COMMUNITY SETTINGS

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Overview

- Review impact of pain in later life
- Summarize four approaches to improving management of later life pain
- Focus on self-management (SM) programs Describe knowledge gaps
  - Present four studies involving translation of SM programs in community setting
- Summarize research/policy issues regarding self-management programs and role for addressing pain disorders (e.g., OA)

Impact of Pain in Later Life

- In persons ages 65+:[2]
  - Primary care: 20%-50%
  - Assisted living: 40-60%
  - Nursing home: 50-80%
- Strong and independent associations with frailty, depression, decreased QOL, impaired functional status, decreased physical function, decreased self-rated health

[1]http://www.iom.edu/Reports/2011/Relieving-Pain-in-America-A-Blueprint-for-Transforming-Prevention-Care-Education-Research.aspx. [2] Helme RD. Clin Geriatr Med 2001,17:417–31. [3]Blyth et al, 2008;140:224-30.

Approaches to Improving Quality of Pain Care in Later Life

- Generate age-appropriate evidence base
- Identify new targets for intervention
- Develop new approaches to deliver pain care
- Translating established interventions into practice
  - Focus on pain self-management programs

Define Self-Management

- What individuals do to manage, adjust to, & minimize impact of chronic condition(s) in context of daily life
- Multiple challenges:
  - Integrate treatment/management approaches for disease and disease-related complications
    - Problem of "competing comorbidities"
  - Deal with emotional sequela occurring as consequence
  - Maintain meaningful life roles in face of disease sequela

Self-Management Education

- Programs/courses/interventions designed to help affected individuals
  - Optimally manage 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
    - Reinforce treatment gains
    - Reminder prompts
    - Encouragement
  - Relapse

Focus on Self-Management in Medical Literature

- PubMed search for 'self-management' in title, abstract or text
  - 1965 30
  - 1985 984
  - 2013 ≈10,000

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 (action plans)

Lorig & Holman. Ann Beh Med 2003;26:1-7.

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

Bandura. Ann Rev Psychol 2001;52:1-26.

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		√	√	√		

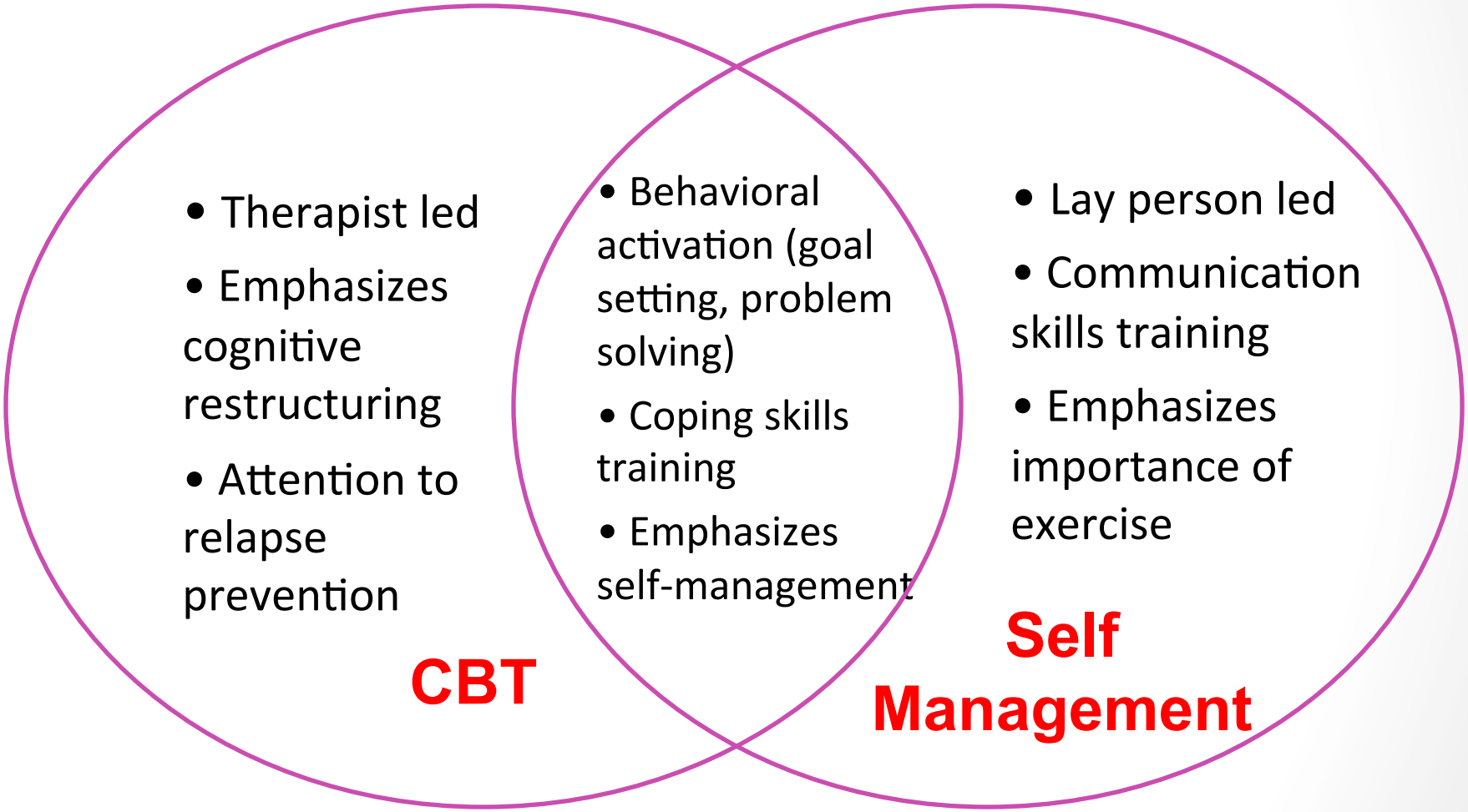
Implementation Sites

- 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 levels
- Large effect sizes: Knowledge gained

Measuring Right Outcomes?

- Osborne & colleagues developed Health Education Impact Questionnaire[1]
- Used concept mapping process gathering data from
  - Individuals with chronic diseases
  - Healthcare professionals
- Generated 42-item instrument with 8 core domains

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

Self-Management Program Effects

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%

[1]Results generated from 142 CDSMP course offerings (N=1,341). [2] Substantial benefit defined as estimated ES ≥ 0.50. Nolte et al Pat Educ Coun 2007;65:351-360.

Groups Endorsing Translation of Self-Management Programs

- 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
- American Geriatrics Pain Society Practice Guidelines for Management of Persistent Pain

Self-Management in Medical Home Model

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

Knowledge Gaps

- Generalizability issues: Evaluations/studies conducted using largely non-Hispanic white populations
  - Limited reach particularly in minority communities[1]
- Problems with program attrition 10-50% average ≈ 25%[1]
- Problems sustaining programs at organizational or agency level[2]
- Problems maintaining treatment effects at individual level[3]

[1]Rizzo et al. 2007. Report New York State Chapter of the Arthritis Foundation; [1]Warsi et al. Arth Rheum 2003;48:2207-13; [2]Townley et al. Pain Med. 2010;11:405-15; [3]Goeppinger et al. Arth Rheum 2007;57:1081-88; [3]LaForest 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: Is program adaptation feasible using community-based participatory approach (CBPR)?
  - Goal: Adapt program for optimal use in minority elders
- Partners (studies 1 & 2):
  - New York City Chapter of Arthritis Foundation
  - New York City Council of Senior Center Services
- Target implementation site = senior centers
  - 12 million seniors currently receive 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 CBPR approach
  - 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 final class 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)

- Study participants generated 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)

Parker et al. Fam Comm Health 2011;35:236-45.

Results (Study 1)

- Community Advisory Board[1] adjudicated recommended changes, board composed of 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 ≈14 hours to complete
- Published method of program adaptation[2]

[1]Parker et al. Fam Comm Health 2011;35:236-45. [2]Chen et al. Eval Health Professions 2012;36:73-92.

Examples of Program Change

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

Parker et al. Fam Comm Health 2011;35:236-45.

Conclusion (Study 1)

- CBPR feasible tool for adapting evidence-based programs in community setting
  - Participants exposed to **all elements of protocol**[1]
- Program changes made reflected participants' preferences/perceived needs
- Did not alter core components

[1]Chen 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 possibly superior outcomes?
- Conducted controlled study
- Participants: Ages 60+ with self-reported arthritis conditions
- Setting: 9 NYC senior centers (implemented adapted or original program but not both)
- Implemented each course 9 times (both adapted and original) = 18 total classes

Methods/Results (Study 2)

- Enrolled 201 adults (71% of eligibles)
  - Equal numbers of African Americans, Hispanics, and non-Hispanic whites
- Measured short- (10 week) and intermediate-term (24 week) outcomes
- Mean age = 74 (range = 60-87)
- Mostly female = 78%
- Over half reported OA as cause of pain (54%)
- Average pain duration ≈8 years

Reid et al. HSS J. 2014 Feb;10(1):59-67. doi: 10.1007/s11420-013-9368-2. Epub 2013 Nov 6.

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

Reid et al. HSS J. 2014 Feb;10(1):59-67.

Results (Study 2)

- Both programs produced clinically and statistically significant increases in primary outcomes:
  - ↓Pain intensity (23%)
  - ↑Mood (18%)
  - ↓ Perceived disability due to pain (RMDQ) (20%)
  - ↓ Fatigue (16%) and stiffness (24%)
- No differences by race/ethnicity group

Reid et al. HSS J. 2014 Feb;10(1):59-67.

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

Reid et al. HSS J. 2014 Feb;10(1):59-67.

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

- Research Questions: Can we adapt evidence-based pain self-management pain program for use in home care
- Rationale: Half of all patients receiving home care report activity-limiting pain[1]
- Physical therapists ideally positioned to deliver
  - Frequently care for patients with activity-limiting pain[1]
  - Voice interest in learning self-management techniques for use when treating patients with pain[2]
- Work conducted in partnership with Visiting Nurse Service of NY

[1]Beissner et al. J Geriatr Phys Ther. 2012; Sept 12, epub ahead of print. [2]Beissner 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 CBT pain protocol; made recommendations for program modification
  - Principal criterion: Feasibility of implementation
- Adaptation committee adjudicated all proposed modifications:
  - Psychologist, pain expert, physical therapists, experts in home care delivery, & research team

[1,2]Beissner et al. J Geriatr Phys Ther 2012;Sept 12. Beissner et al J Aging Phys Ther 2011;20:246-65. [3]Beissner et al Phys Ther 2009;89:456-69.

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 care[2]
  - Feasibly implemented with high treatment fidelity
  - High patient and PT satisfaction with protocol

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

Study 4 (Ongoing)

- Cluster RCT to test effectiveness of adapted pain protocol (vs. usual care) in home care
- Participants: Ages 60+ 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 (Ongoing)

- 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 ½ day training sessions (N≈175)
    - Online video podcasts available for reinforcement
    - Six-month reinforcement sessions completed with all PTs in active intervention arm
    - Monthly emails to PTs in intervention arm as reinforcement
  - Completed enrollment of 600 home care patients

Summary of Community-Based Studies

- CBPR effective tool to adapt and implement pain self-management programs at community level, leveraging...
  - 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

Research/Policy Issue Summary

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

Research/Policy Issue Summary

- Program maintenance at agency and/or 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

Research/Policy Issue Summary

- 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 programming[1]
  - Demonstrating ability to offer quality programming with associated positive outcomes will help providers[2]
  - Building capacity for program delivery in systematic (vs. sporadic) fashion also likely to help[2]

[1]http://collectiveactionlab.com/sites/default/files/PCP%20Research%20NCHM.PDF
[2]Ory M. J Am Geriatr Soc 2013;61:821-3.

Research/Policy Issue Summary

- Self-management approaches successfully implemented in primary care in **efficacy** studies[1]
  - Successfully delivered by nurse case managers (Stepped Care for Affective disorders and Musculoskeletal Pain or SCAMP trial) [1]
  - Moderate to strong effects for pain reduction and pain-related disability
- Large **effectiveness** trial (N=5,599) was negative[2]
- Efforts needed to determine how best to integrate SM support into primary (and other healthcare) settings

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

What Does Program Success Look Like?

Cornell-Based Translational Center on Pain and Aging

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TRANSLATIONAL RESEARCH INSTITUTE ON PAIN IN LATER LIFE

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Questions & Answers