

Taking Community Action Against Pain: Translating Research on Chronic Pain among Older Adults

One of CITRA's goals is to develop forums that facilitate a continuous loop of communication between researchers and practitioners. These forums are designed to create a shared conception of aging-related problems and solutions between the two groups.

This one day CITRA NYC conference on October 16, 2006, was designed to stimulate dialogue among researchers, practitioners, and policy makers on this important topic. One anticipated outcome of this endeavor is the formation of community-researcher partnerships to address the problem of chronic pain among older adults residing in NYC.

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SUMMARY OF CITRA'S NYC CONFERENCE ON OCTOBER 16, 2006

TARGET AUDIENCE

- Health care and social service practitioners who provide care for older New York City residents;
- Researchers interested in chronic pain and/or community-based participatory research.

Designed as an invitational forum to maximize networking and brainstorming, eighty researchers and practitioners from the NY metropolitan area attended this over-subscribed conference, with many more wait-listed.

OBJECTIVES

To impart knowledge regarding:

- Innovative community-based strategies for managing pain in older adults;
- Influence of race/ethnicity and culture on the pain experience;
- Role of religion as a strategy for coping with chronic illnesses such as chronic pain;
- Collaborative models of research that involve community practitioners and researchers and build on the unique strengths, knowledge and resources within a given community; and
- Opportunities for future collaboration on community-based research projects on chronic pain in older persons.

BACKGROUND OF PROBLEM

As many as 50% of community-dwelling older adults report experiencing chronic pain, which is most often caused by arthritis and arthritis-related diseases among adults aged 65 years and above. Chronic pain frequently leads to substantial health and social problems including depression, decreased quality of life, and social isolation. One of the most dreaded consequences of this disorder is loss of functional independence. The physical and emotional distress that occurs as a consequence of chronic pain often undermines an individual's confidence in their health.

Chronic pain is often undertreated in elderly adults; advancing age, frailty, and belonging to an ethnic minority group increase risk for undertreatment. A variety of non-drug treatments for chronic pain including exercise and other self-management programs have been shown to reduce pain, improve both quality of life and functional status among older adults. Despite their demonstrated success and appropriateness for use in the community, the interventions have reached less than 1% of US adults with chronic pain.

Efforts are therefore needed to develop optimal strategies for implementing effective pain programs in diverse community settings and to identify barriers and facilitators to implementation. For example, race/ethnicity has been recognized as an important factor influencing individuals' preferred strategies for managing pain. Failure to understand and incorporate cultural aspects regarding pain management may be an important implementation barrier. The role of religion in appraising the meaning of and coping with chronic pain in later life is another important but understudied dimension of the pain experience.

This conference was designed to educate participants about innovative community-based pain treatments and the influence of race/ethnicity and religion on managing pain; promote meaningful dialogue between community practitioners and researchers about chronic pain in older adults; and encourage development of practitioner-researcher partnerships to address this important problem.

PRESENTATIONS

Making the Case for Community Action Against Chronic Pain

Cary Reid, MD, PhD, Associate Professor of Medicine, Weill Cornell Medical College, New York, NY

The cause of chronic pain in older adults—defined as the presence of a persistent unpleasant sensation often defined as pain, ache, burning, discomfort and lasting for at least a two month duration—can involve musculoskeletal disorders (>75%), nerve disorders or other factors (e.g., depression, features related to osteoporosis). This common problem—affecting 30-65% of community dwelling older adults—negatively impacts on physical, social, psychological and economic function. Treatments for chronic pain include analgesic medications, physical therapies, surgery, cognitive-behavioral therapies and other management approaches, e.g., complementary therapies, activity restriction and prayer. The following illustrates the personal suffering experienced by older adults with chronic pain:

“It’s horrible. I can’t do the things I used to be able to do because of the pain. I am terribly depressed because I cannot take part in activities that bring meaning and joy to my life like going to museums and to shows. Now it takes everything I have to walk two blocks because of the pain.” – 82 year-old female with chronic back pain.

“It’s simply unbearable. You try to focus on other things/activities but the pain is always there. I have days when I think it is no longer worth living because of the pain. The medications only help a little and cause more problems than real relief. I am frustrated beyond words by having to live with pain on a daily basis.” —86 year-old with posttherpetic neuralgia

Because of the prevalence of this problem and the deleterious effect on quality of life and function, Congress declared 2000-2010 the “Decade of Pain Control and Research.” Soon afterwards, the Joint Commission on Accreditation of Healthcare Organizations released pain standards in 2001. These standards called for facilities to: 1) recognize and address patients’ right to adequate assessment and treatment of pain; and 2) assess for compliance as part of accreditation process. Several large healthcare organizations have adopted pain assessment as ‘fifth vital sign’.

Despite this advocacy and attention, the problem of chronic pain in older adults is pervasive. Many older adults have persistent pain despite treatment. Some self-management programs are not widely available. And some older adults do not seek help at all for a variety of reasons including negative interactions with healthcare providers.

Additional research is needed to address the multiple dimensions of the chronic pain experience and to understand ways to make effective self-management interventions more available to older adults. Community based participatory research (CBPR) is one new promising approach to these

problems. This is a partnership approach that *equitably* involves community members, organizational representatives, and researchers in all aspects of research process. Partners contribute expertise and share responsibility and ownership to enhance understanding of research problem. Knowledge gained is integrated with action to improve health and well-being of community. In addition, CBPR recognizes community as a unit of identity. This can be a geographic area or individuals with a shared problem or interest in the problem. It builds on strengths, resources, expertise in community, promotes co-learning throughout all phases of research and emphasizes the dissemination of findings to community in order to effect change.

Few studies have utilized CBPR to address problems faced by older adults. One study developed and implemented culturally sensitive self-management program for adults with diabetes mellitus (Ingram et al. *Prev Chronic Dis* 2005;2(1):1-12). Positive outcomes included improved knowledge and self-management behaviors among attendees. It was also used successfully to implement physical activity programs for seniors in culturally diverse senior centers (Stewart et al. *Prev Chronic Dis* 2006;3(2):1-20 and was used by a coalition of healthcare organizations and social service agencies who worked together to improve chronic care delivery for seniors (Alkema et al. *Fam Comm Health* 2003;3:221-9).

Weill Medical College of Cornell University's Division of Geriatrics and CITRA have applied for funding to the National Institute of Nursing Research to use CBPR to counter the underutilization of self-management programs for pain. Partnering with three community agencies serving three different ethnic groups in New York City, the proposed program would: 1) form a Steering Committee to guide work comprised of seniors with pain, senior center personnel, researchers, and other community members with expertise; 2) survey senior chronic pain sufferers to identify barriers to program engagement; 3) survey senior center personnel & other community experts to identify barriers to implementation; 4) modify programs (as needed) and pilot test them; and 5) disseminate findings to community and other relevant audiences. The anticipated outcomes of the project include the identification of barriers to pain program engagement and implementation; culturally and age-appropriate self-management programs for pain and enhanced community and researcher capacity.

In summary, CBPR—a highly promising community action approach—requires community practitioners and researchers to work together. It has substantial potential to address chronic pain (and other age-relevant) problems at community level.

Race differences among elderly adults presenting for chronic pain management from the clinic to the community.

Tamara A. Baker, PhD, Assistant Professor, School of Aging Studies, University of South Florida, Tampa, FL 33620

Projected increases in the number of older adults in the United States has generated concern regarding the adverse impact certain medical conditions and symptoms have on the abilities of adults to function physically and psychologically within the context of their environment. Chronic illnesses such as high blood pressure, diabetes, stroke, cancer, and arthritis often lead to pain symptoms, physical limitations, poor physical health, and psychological perturbations for many aged adults. Despite the prevalence of these medical conditions, chronic pain, which is the cardinal symptom for many medical diseases, is not well-defined among elderly adults, particularly those from diverse race and ethnic populations. Although the biological sensations of

pain are universal, the meaning and responses toward the pain experience differ across various race groups.

This presentation focused on the influence race and culture has on the pain experience in general, particularly among the elderly from diverse populations. Several studies were presented defining disparities in the management of chronic pain among clinic- and community-based samples, why such disparities exist, and what can be done to potentially reduce the disparities gap. Aside from presenting findings from these quantitative studies, the audience had the opportunity to view results from a recent project employing a qualitative method, *Photovoice*, which served as a participatory needs assessment for an elderly clinic- and community-based sample of chronic pain patients. This methodology explored everyday life of chronic pain patients through images and written narratives. The objectives were to qualitatively assess what everyday life is like with chronic pain and to facilitate a sampling of chronic pain patients from different social (clinical and community-based) and behavioral settings.

Pain Coping Skills Training for arthritis pain: Training nurse practitioners to bring the treatment into community settings.

*Joan E. Broderick, PhD, Assistant Professor of Psychiatry & Behavioral Science
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University, Stony Brook, NY*

The leading cause of disability in the U.S. is arthritis, affecting approximately 60% of those over 65 years of age. Biomedical treatments are limited in their ability to curb arthritis disease progression and to eliminate pain and functional impairment. Efficacy trials have documented that Pain Coping Skills Training (CST) for arthritis reduces pain, improves physical and social functioning, increases self-efficacy, and reduces psychological distress. CST, based on cognitive-behavior treatment, trains patients in behaviors and strategies that can reduce chronic pain. Despite the efficacy of CST documented in the literature, it has not been translated into community practice and is unavailable to the vast majority of arthritis patients.

Increasing patient access to CST interventions will require an innovative delivery model. Nurse practitioners (NP), with their training in patient education, seem well-suited to deliver CST. Preliminary work has been conducted to lay the groundwork for the first RCT effectiveness trial –bringing CST from academic medical settings into community rheumatology offices where NPs will be trained to deliver manualized, 10-session CST. The pilot study demonstrated the feasibility of training NPs to deliver CST and yielded pre-post change scores on clinical outcome measures that are comparable to the improvements reported in the efficacy literature, thus suggesting the potential for effective translation of CST into the community. Treatment fidelity was confirmed based on 80% adherence (across patients and 10 sessions) to therapy manual curriculum. Patient satisfaction with CST and NP were both > 4 on a 5-point scale.

Based on the success of the preliminary work, a large-scale multi-site effectiveness trial is planned to investigate this NP delivery model for pain management in community rheumatology settings. Study design has incorporated RE-AIM guidelines to enhance data collection pertaining to issues of effectiveness in the community and dissemination.

Religiousness and spirituality as community resources for aged persons with chronic illness.

Ellen Idler, PhD, Professor of Sociology, Department of Sociology, Institute for Health, Health Care Policy and Aging Research, Rutgers University, New Brunswick, NJ

Religiousness and spirituality are both subjective, internal resources of individuals and also public, social resources of communities, in the form of religious congregations. The connection between religion and physical health goes back to some of the earliest empirical research in the social sciences, but it has taken a big upsurge in the last decade or so. Religious group membership and individual religiousness/spirituality have both been associated with an array of physical health outcomes, many of which are associated with symptomatic pain, but very few studies have addressed the issue of religiousness and pain directly. One observation frequently made about this research is that religiousness/spirituality (as the hybrid term implies) is a multidimensional phenomenon. Evidence from published reviews of the field, and several of our research projects, shows that different dimensions of religiousness/spirituality are related to different health outcomes. Several studies were presented in which alternative dimensions of religiousness/spirituality are related to disability outcomes in a representative community sample, to identity and self-ratings of health in a disability clinic population, to quality of life in a last year of life sample, and to self-reported pain in a heart surgery sample.

Translating the findings of such research would mean reaching out to religious communities and their leaders, chaplains, and local congregations. Congregations represent unique social resources that provide support and services for their own members, as well as an institutional base for outreach to others in the community. The volunteer backbone of many of our secular voluntary organizations is made up of members of religious congregations. Moreover, many of our most innovative social institutions that provide care for the chronically ill, the elderly, and the dying, have had religious origins; the paradigmatic example would be hospice care.

The Chronic Pain Self-Management Program: One approach to community care.

Sandra LeFort, PhD, RN, Director and Associate Professor, School of Nursing, Memorial, University of Newfoundland, St Johns, Newfoundland, Canada

Over 20% of community dwelling adults suffer from chronic non-cancer pain such as musculoskeletal pain, arthritis, chronic headache, and other conditions. Surveys highlight the burden of chronic pain on the lives of sufferers including functional limitations and high rates of depression, sleep problems and low self-esteem. It also has a high economic cost to the person with pain and to society as a whole. Despite the high prevalence and severe impact of persistent pain however, access to specialized pain services remains limited, with only 1.1% of Americans with chronic pain being treated by a specialist health care provider.

While the onus is on primary care providers to fill this gap in care, most have had little training in pain management and know little about self-management as a strategy. To address this need, a low-cost, accessible, community-based chronic pain intervention, the Chronic Pain Self-Management Program (CPSMP), was developed that is based on the successful Arthritis Self-Management Program by Kate Lorig at Stanford University. The goal of the 12-hour group CPSMP is to give people the skills and confidence to better manage their chronic pain to improve their every day quality of life. Two randomized clinical trials (RCTs) of the CPSMP have been conducted in Canada and provide evidence of its efficacy and effectiveness in adults,

including older adults. A brief description of the CPSMP content and process, the RCT results, and lessons learned about delivery models for sustainability in the community was presented.

COMMUNITY PRACTITIONER PANEL

Why partner with researchers? Three community practitioners' views.

• Evelyn Laureano, PhD, MSW, Executive Director, Neighborhood Self Help by Older Persons Project, Inc., Bronx, NY

• Julia Schwartz-Leeper, LMSW, Executive Director, Riverdale Senior Services, Bronx, NY

• Josie M. Piper, RN, MA, Site Director, Central Harlem Senior Citizen's Coalition, Inc., New York, NY

Each of the three presenters described their senior centers, the communities they serve and the importance of the centers in the lives of older adults. While each center is unlike the others in size, staffing, programming and populations served, each saw benefits to partnering with researchers as a way to: 1) bring pain management programs to older adults; 2) contribute to the knowledge base on the topic; and 3) better position their centers for future funding opportunities.

GENERAL DISCUSSION

Conference participants discussed their thoughts and ideas about research priorities and directions on the topic of chronic pain in older adults, ideas about dissemination of promising practices and attending a roundtable discussion about chronic pain to be held in the near future.

FEEDBACK FROM PARTICIPANTS

- Fifty three participants (66%) submitted feedback forms at the end of the conference. Of these:

91% thought the information presented at the conference will be relevant to their practice;

94% thought the conference met their expectations;

60% thought it would alter their practice performance; and

36% did not think the conference would alter their practice but confirmed their current practice.

- In addition, participants reported gains in knowledge as a result of the conference:

Q. How would you rate your knowledge of this topic before this event?

<i>response category</i>	<i># of responses</i>
Excellent	3
Good	22
Fair	25
Poor	3

Q. How would you rate your knowledge of this topic now?

<i>response category</i>	<i># of responses</i>
Excellent	13
Good	40
Fair	0
Poor	0

- The following comments illustrate the overwhelming positive sentiments expressed on the feedback forms:

“Provided inspiration for program development. Ample practical and pragmatic recommendations.”

“Enlightening, professional, thought-provoking.”

“I will focus more on integrating pain management training and CBT in my practice.”

“Very good food for thought. Starts me towards developing research questions....”

“Helps me to view pain and its effects differently.”