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Implementing a Cognitive-Behavioral Pain Self-Management Program In Home Health Care Part 1: Program Adaptation

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Keywords

Pain Self-Management; Older Adults; Home Care; Physical Therapy

INTRODUCTION

Pain is a leading cause of disability in later life.^{1, 2} The physical and emotional distress that occurs as a consequence of pain often undermines individuals' confidence in their health, and is associated with increased utilization of health care services, long-term nursing home residence and lower quality of life.^{3, 4} Despite its prevalence and impact,^{1, 2, 5} pain remains inadequately managed among older adults and is a major problem in home health care. Over half of all home care patients discharged in 2004 and 2005 had activity-limiting pain on admission, and more than one third reported the same or worse pain on discharge,⁶ thereby providing strong support for efforts to reduce pain-related disability in this target population.

While analgesic medications are by far the most widely administered pain therapy, the costs and side effects associated with many analgesic treatments, as well as the potential for drug–drug interactions, pose significant limitations to this treatment approach, particularly among older adults.^{7, 8} Furthermore, many pain medications cannot be prescribed because of co-occurring morbidities (e.g., congestive heart failure, peptic ulcer disease, disorders requiring anti-coagulant therapy), which are common among individuals receiving home care services. In addition, patient concerns about analgesic medication-related side effects, as well as other concerns about long-term analgesic use (e.g., cost, fear of addiction), lead to low adherence with this treatment approach in diverse populations of older patients with pain.⁹ Finally, even among patients who derive some relief with analgesic medications, substantial disability persists.^{10, 11} These data provide strong support for efforts directed at improving the management of pain in the home care setting.

Cognitive–behavioral therapy (CBT) is a well-developed, evidence-based strategy for the mitigation of pain and preservation of physical functioning. The cognitive–behavioral approach to pain management is based upon the premise that an individual's beliefs and

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attitudes affect their behaviors, that these interact to affect the pain experience, and that individuals can learn and adopt new ways of thinking and feeling that will improve their behavioral responses to pain. CBT seeks to enhance a person's control over pain using a variety of psychological strategies and emphasizes the individual's role in controlling pain.¹² CBT is typically provided by psychologists and has proven efficacious for reducing pain and disability levels among persons with diverse persistent pain disorders.^{9, 12, 13}

A cognitive-behavioral pain self-management (CBPSM) program developed by study investigators (Beissner and Reid) and implemented in senior centers combines principles of CBT, pain management strategies such as relaxation and goal setting, and physical exercises to improve physical function and mobility of older adults with persistent back pain. In an uncontrolled study, approximately 70 older adults showed significantly reduced pain-related disability, improved self-efficacy, and high levels of program satisfaction following the eight week program.¹⁴

The senior center CBPSM program was designed and implemented for older adults with persistent back pain, but prior research indicates that exercise and cognitive-behavioral therapies are beneficial for a wide range of pain problems.^{12, 13, 15} Since the great majority of older home health patients is homebound with multiple functional limitations and mobility impairments,^{6, 16} accessing this type of pain management program within the community is not feasible for these vulnerable older adults, even if such programs were widely available. Prior research has shown that an individual, home-based, cognitive-behavioral therapy program is feasible and acceptable to older persons with back pain problems,¹⁷ but this type of program is not widely available.

Physical therapy is more widely available and PTs working in home health care commonly treat patients who have pain problems that slow progress towards achieving treatment goals. Treatments included in the senior center CBPSM program (relaxation techniques, goal setting, breathing strategies, and work adaptation (e.g., activity pacing) are areas of physical therapy practice¹⁸ and entry-level physical therapy curricula include instruction in these areas.¹⁹ While only a minority of PTs currently use these techniques when treating patients with chronic pain, they express a high level of interest in incorporating them into their treatment programs for this patient population.²⁰ We therefore sought to adapt the senior-center CBPSM program for delivery by physical therapists in an effort to reduce pain-related disability and improve patient outcomes in home care.

PURPOSE AND METHODS

In this paper we describe the adaptation of the senior-center CBPSM program for delivery by home health physical therapists within the context of usual physical therapy care. Specific adaptation steps included: (1) gathering feedback about the program and how it could be optimally adapted for use by home care PTs; and (2) asking two interdisciplinary expert panels to review the data generated in step 1 and make final decisions regarding the adaptation of the evidence-based program for use in the home care environment.

Setting

This translational study was conducted at the Visiting Nurse Service of New York (VNSNY), the largest nonprofit home care organization in the U.S. VNSNY has an average daily census of roughly 28,000 patients and a staff of approximately 2,100 nurses, 475 rehabilitation therapists, 550 social workers, and 8,000 home health aides. It serves individuals living in and proximate to New York City, including large numbers of minority older adults. In 2008, 24.4% of the patients served in the Adult Home Health Program at VNSNY were African American, 21.5% Hispanic, 5.0% Asian, and 49.1% white or other.

The majority of home care patients are Medicare beneficiaries. To be eligible for Medicare-funded home health care an individual must be: (1) homebound, (2) medically in need of home health care (i.e., have a need for intermittent or part-time skilled care to treat their illness or injury), and (3) under a physician's plan of care. No prior hospitalization is required although the majority of beneficiaries are hospital patients before home health admission. The services provided can include skilled nursing, physical therapy, occupational therapy, speech-language pathology services, medical social work, and aide service. In 2011, the most recent year for which data are available, 3.4 million individuals received Medicare home health services from almost 12,000 home care agencies.²¹

Senior Center Program Adapted for Use in Home Care

The senior center-based program was designed for older adults with persistent back pain with 10 – 15 participants in each group.¹⁴ The program consisted of eight 90-minute sessions that included pain self-management content, exercise, and additional educational topics relevant to older adults seeking a more active lifestyle. (Program content is shown in Table 1.) There also were participant handouts with brief descriptions of the material covered in each class. The program leader was an exercise expert with more than 20 years of experience working with older adults. An instructor's manual provided teaching "scripts" and activities for each session.

Adaptation Process

Program adaptation is increasingly recognized as an essential component in the implementation of evidence-based practice.^{22, 23} Successful adaptation of a program depends on both the practical aspects of implementation within the targeted setting and the integrity of the program itself. For this project, workshops with potential program providers (PTs working in home care) were convened to gather input on the practicality of implementing the program in their practice. An expert panel reviewed input from the workshops and provided guidance on translating the program for use in home health care while maintaining program integrity.

Provider Input—Two groups of home-care PTs working in different geographic regions of New York City were recruited via email announcement to participate in this observational study. The areas selected, Staten Island and Manhattan, were chosen because they differ in population density, racial/ethnic diversity, and means of staff travel to patient homes and we wished to gain a broad range of perspectives on the CBPSM program.

PTs were invited to attend a 4-hour workshop in their region to learn about the cognitive-behavioral approach to pain management, and to provide feedback about how best to adapt the senior center program for use in home care within the framework of usual physical therapy. The only eligibility criterion was employment by VNSNY. PTs were offered continuing education credit associated with the educational portion of the workshop which served as an incentive for some participants. Prior to attending the workshop, each PT received a brief summary of the literature on CBPSM.

Two instructors jointly delivered the four-hour workshop program. One instructor was a PT with expertise in home care administration and quality assurance, the other was the PT who developed the original CBPSM program and had prior experience in home care.

The workshop began with a brief summary of selected literature supporting the use of the cognitive-behavioral approach for pain control and an overview of the rationale for translating the pain self-management program into physical therapy home care. Participants then were provided with the educational materials used in the original program, and each component of the program was reviewed. Opportunities to briefly practice the techniques were integrated into the session, and therapists were encouraged to ask questions and seek clarification as needed.

After the entire program was presented, therapists completed a written survey on 1) the program components they felt were likely to be the most helpful for their patients; 2) their suggestions for modifying the educational materials for use with home care patients; and 3) the resources and support that would be needed to implement the program effectively. Questions were asked in an open-response format; for example the first item read: "What aspects of the cognitive-behavioral pain management program do you think will be most helpful for your patients?" Basic demographic information (e.g., years of experience and race/ethnicity) was also collected. Following completion of the surveys, the presenters led a group discussion to allow participants to share their own thoughts and hear and reflect upon others' perceptions of the pain self-management program.

Expert Panels—Data from the workshops first were distributed to an interdisciplinary team, including PTs experienced in home care, a physician with expertise in geriatric pain management, an expert in home care administration, and individuals with research expertise. Two panel members were involved in the development and implementation of the original senior center program. Data provided for review included notes from session presenters and summaries of therapist written feedback. Expert panelists met to discuss the findings and made recommendations for program modifications. These recommendations were incorporated into a revised training manual and patient education materials.

The revised program was presented to a wider research consortium with expertise in chronic disease management interventions, including social scientists, physicians, and a health psychologist. This consortium meets monthly for a "works in progress" seminar, with approximately 20 participants gathering in-person or via video-conference and teleconference technologies.

Data Analysis

Data from the written surveys were independently classified and categorized by two raters, who then met to reconcile differences. These results were then cross-checked with the presenters' notes taken during each session to ensure inclusion of all ideas. Simple statistics were estimated to describe demographic and survey results.

RESULTS

Provider Input

Seventeen PTs attended the two workshops and completed the written survey. Therapists had an average of 16.6 years of practice experience (S.D. = 6.3; range 8–29 years); and an average of 9.5 years in home care (S.D. = 5.6; range 1 – 20 years). Ten therapists self-identified as white, non-Hispanic; 5 as Asian; and 2 declined to complete the race/ethnicity question.

At the end of the educational session PTs were asked several open-ended questions, beginning with: “What aspects of the cognitive behavioral pain management program do you think will be most helpful for your patients?” Activity pacing, relaxation, diaphragmatic breathing, and imagery were the most commonly endorsed techniques. No therapists identified sleep tips, or strategies for program maintenance as among the most valuable strategies (Table 2).

The next open-ended question concerned the patient written materials. PTs were asked: “Should these be modified for use in home care and if so how?” Responses included comments about: (1) the amount of content presented (e.g., “the written program has to be condensed and curtailed to allow patients to stay focused and interested”); (2) the readability of the materials (e.g., “the font size needs to be larger,” “more simple language should be used”); and (3) the need for enhanced visual interest (e.g., “I would use more color,” “include pictures or diagrams together with each specific instruction”). There were differences of opinion regarding the best format for providing written materials to patients (e.g., individual sheets for each topic provided when it was being taught versus a booklet format with all content given to patients at the beginning of the program).

PTs also were asked: “What kind of support do you need to feel comfortable using this program with your patients?” A number of suggestions were made regarding internet-based resources (e.g., “an on-line reference with a visual component may help to reinforce techniques,” “a chat room to share experiences or an open blog to discuss problematic patients,” “on-line resource – training manual”). Other comments included changes to training (e.g., “could show a quick video of implementing with a patient,” “more demonstration,” “documentation tips,” “include training for minimally to moderately cognitively impaired patients”) and policy changes.

Expert Panels

Members of the first expert panel reviewed the data collected during the two PT workshops prior to a meeting convened to discuss the findings. At the meeting, discussion centered on

the PTs' input as well as the administrative feasibility of the CBPSM program. It was noted that PTs providing home health care at the study agency are required to develop an exercise or instructional program individualized to each patient's needs. This program replaced the standardized exercise component of the original program. Home care administrators noted that many patients admitted with activity-limiting pain would be discharged from physical therapy before an 8-session program was completed. Considerable discussion revolved around which program components to delete if the program was reduced in length. The panel made recommendations for program modification based upon therapist comments as well as their own perspectives.

Prior to the "works in progress" seminar, background material and the revised intervention protocol were distributed to participants. The material was briefly summarized at the beginning of the seminar. After discussion, this group recommended no further modification of the program.

Program Adaptation

As noted above, practicality is a key consideration when adapting a program to a new setting. A major issue in our adaptation was the ability of therapists to implement the program as part of their current practice given no additional funding for the program. Therapists were concerned about the number of sessions in the original program, and time required for content delivery within each session, considering the other physical therapy goals that must be addressed in each patient visit. Based upon these comments and a review of the number of PT visits typically provided to home health patients, the program was decreased from 8 to 6 sessions.

To make implementation of the program feasible over 6 sessions, it was necessary to delete some content. Using data from therapists regarding their perception of the most valuable strategies, patient instruction in pacing, diaphragmatic breathing, relaxation, imagery and goal setting/analysis were retained. Therapist comments during group discussions revealed that many patients have concerns with sleep, so sleep tips content was also retained. Therapists and experts alike considered the content related to the impact of thoughts and emotions on pain to be important and a valuable part of the program. However, because of the uncertainty about the effectiveness of short-term interventions in actually changing negative thought patterns,²⁴ and workshop participants' concerns regarding their preparedness for delivery of this content area, it was deleted. The research team also made modifications to the structure and sequence of the instruction based upon expert input and incorporated these changes into a revised training manual and patient education materials.

In summary, the vast majority of the PTs' recommendations were incorporated into the revised program. Those recommendations that were not incorporated were deemed impractical to implement due to budgetary constraints. Comments on the patient materials were incorporated into the revised patient handouts yielding a packet of content with 1–2 pages per program component, written at the 4th grade reading level, using color graphics. Table 3 provides a list of the major changes in the original program and the rationale. The final adapted program content and individual session sequence are shown in Table 4.

DISCUSSION

This paper describes the process used to adapt a successful community-based program for implementation in a different program setting by different program providers. Based upon a systematic review of the literature on translation of evidence-based programs (EBPs), Krivitsky and colleagues defined a 6-step process for program adaptation.²⁵ The process incorporates a literature review to identify EBPs to meet the needs of a targeted population, a needs assessment to determine the extent of the problem, direct feedback on the selected evidence-based intervention, gathering input on the program by content experts, adaptation based upon feedback, and pilot testing of the adapted program.²⁶ Since members of the translation team developed and implemented the CBPSM program in another setting, and the research team had a strong history of collaborative work on pain management in home care, this program translation process focused on gaining direct feedback on the original program, input from content experts, and program adaptation.

While the process of program adaptation varies according to the program and target audience, a concern with any program revision is that the essential elements of the intervention be retained. Typically, in program translation new content is added to address the specific needs of the target audience.²⁵ In the present project, implementing the CBPSM program within the context of usual home care physical therapy required the deletion of content, including the impact of thoughts and emotions on pain perception and pain behaviors. This particular content area, based upon cognitive restructuring, was perceived to be important for some patients. While addressing the impact of thoughts and emotions on pain and pain behavior is central to most CBT protocols, it is unclear whether this intervention can be effectively delivered in short-term programs such as ours. This uncertainty, coupled with concerns about PTs' preparedness to deliver this content and the need to shorten the number of sessions, led us to delete this topic.

During workshop discussions a number of suggestions were made regarding resources that could help PTs deliver the program effectively. Some suggestions were implemented (e.g., a video was developed to demonstrate integration of the content into a physical therapy home visit), while others were not. For example, on-line training resources were suggested as a means of refreshing therapists' knowledge and skill in delivering the program. These suggestions were deemed valuable by the expert panel, but resource constraints limited our ability to develop and implement this support for the initial implementation of the program.

The process used for program adaptation provided for input from a key stakeholder group, home health physical therapists, which helped to identify potential barriers to subsequent implementation efforts. While members of the research team have experience in home care, this does not replace the current experience of those practicing in this complex setting each day. Our second source of program input was two expert panels that weighed the issues raised by the PTs against the need to maintain program integrity. The expert panels carefully considered the issues identified in the workshops and accepted the vast majority of the recommendations. We anticipate that listening to the concerns voiced by workshop participants and adjusting the program accordingly will help to facilitate buy-in to future groups trained in the program and will minimize the barriers to effective program delivery.

This study has several limitations that warrant consideration. At this time, no gold standard exists for adapting health promotion programs into new delivery settings. Other approaches for garnering suggested program modifications and implementing program changes could have led to different results and changes to the original program. However, we deemed the PTs to be the stakeholder group best able to suggest changes for program translation into home care. Other stakeholder groups, like older adults receiving home-care services, may have provided different feedback, leading to different changes in the program. Finally, this study was carried out with PTs working in a large urban home health agency. The results of this adaptation process may not be generalizable to PTs working in smaller or rural organizations. In addition, the race/ethnicity mix of therapists participating in this adaptation process is likely not representative of all areas in the US. We were unable to locate published national data on the characteristics of PTs working in home care to determine the extent to the characteristics of the PTs in our sample differ from those for the nation as a whole.

By incorporating input from program providers and individuals representing concerns of home care administration we sought to identify potential barriers to program implementation. We deemed this input to be equally important to that of program content experts because of the complexities of implementing evidence-based interventions in decentralized practice settings such as home care. PTs working in this environment have less direct contact with supervisors and co-workers with whom to share ideas regarding patient treatments than therapists working in more traditional clinical settings. Since peer teaching and mentoring play a large role in the integration of new skills into clinical practice,²⁷ it is likely that the uptake of new interventions following training may be different than might be experienced in practice settings that allow for greater interaction among colleagues.

CONCLUSION

This paper reported on the process for adapting an evidence-based pain management program for delivery in a new setting (home care) by different providers. The end result of this process is a six-session program with printed patient education materials for delivery in homecare. The next phase of this work focused on field-testing the program in this new setting to determine the feasibility and acceptability of the program to both patients and their providers, as described in Part 2 of this work. Future work will assess the impact of the adapted program on patient pain and disability.

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Table 1**Cognitive–Behavioral and Exercise Therapy Techniques in Original Program**

Session	Cognitive–behavioral content	Exercise/other content
1	Pain theories Introduction to goal setting	Importance of exercise overview Learn warm-up stretches
2	Goal setting – making specific plans to achieve goals Relaxation – Diaphragmatic breathing	Practice stretch exercises Learn new set of stretches
3	Recognizing automatic thoughts and emotions	Importance of body posture Learn walking exercises Learn techniques to monitor exercise intensity
4	Evaluating automatic thoughts Use of positive thoughts Visual imagery	Body mechanics Review and practice above exercises, introduce strength/balance exercises
5	Pleasant activity scheduling	Practice exercises listed above
6	Time-based pacing Progressive muscle relaxation	Learn about importance of adequate hydration Practice exercises listed above
7	Sleep tips	Practice exercises listed above
8	Overall review Present strategies for program maintenance	Relapse prevention Managing future pain flare ups Practice exercises listed above

Table 2

Strategies Identified as “Most Helpful” on Written Survey.

Program Strategy	Number of Responses*
Activity Pacing	9
Relaxation	9
Diaphragmatic breathing	8
Imagery	7
Recognizing/modifying negative thoughts and emotions	5
Setting/analyzing goals	3
Pain theory	3
Pleasant activity scheduling	1
Sleep tips	0
Relapse prevention	0
Program maintenance	0

* Open format allowed listing of multiple strategies. All 17 respondents provided a response to this question with a range of 1 to 4 strategies listed.

Table 3

Summary of Program Changes

Change	Rationale
Program addresses general pain problems, not just back pain	Exercise and cognitive-behavioral therapies are beneficial for a wide range of pain problems. Pain of different etiologies contributes to decreased activity and functional limitations in the frail, older home health population. Effective pain self management is critical for preserving mobility and functional abilities.
Number of sessions reduced from 8 to 6	Number of program sessions needed to be reduced to fit within the usual number of physical therapy sessions in home care.
Deletion of content areas.	Reduction in number of sessions necessitates reduction in the amount of content delivered. Content deleted included: recognizing automatic thoughts and emotions, evaluating automatic thoughts, and use of positive thoughts.
Group exercise changed to individualized exercise prescription	Patients receiving home care have a variety of physical impairments, while those in the senior-center-based program all had lower back pain. Individualized exercise is a fundamental part of PT practice with therapists developing programs specific to each patient's impairments and functional limitations.
Patient handouts modified	Eliminated content in areas deleted from program Modified writing for 4 th grade readability Used color in diagrams to increase visual interest Added diagrams for breathing exercises Increased font size
Training program developed for home health PTs	Incorporated practice of techniques – deep breathing, muscle relaxation, visual imagery Developed video to demonstrate integration of content within a home care session Included training on patient clinical record documentation

Table 4

Adapted Program

Session	Pain Self-Management Content
1	Pain theory Goal setting/analysis
2	General relaxation Deep breathing
3	Imagery Pleasant activity scheduling
4	Progressive muscle relaxation Activity pacing
5	Sleep tips Relapse prevention
6	Review/Reinforcement