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Participatory Adaptation of an Evidence-Based, Arthritis Self-Management Program: Making Changes to Improve Program Fit

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Abstract

We employed community-based participatory research techniques to adapt an evidence-based Arthritis Self-Help Program (ASHP) for older African American, Hispanic and non-Hispanic white adults. Participants and instructors provided multiple recommendations for program changes in telephone interviews and focus groups. Recommendations were adjudicated and implemented through a collaborative, consensus-based process involving diverse stakeholders. Changes implemented show sensitivity to the preferences and needs of participants, as well as the strengths and constraints of program instructors and host sites. Improved fit for participants may extend the program's reach and effectiveness for older adults of color. In addition, the adapted ASHP may make the program more feasible and therefore sustainable for the host sites.

Keywords

Community-based participatory research; program adaptation; program implementation; race/ethnic minority populations

INTRODUCTION

Approximately 46 million adults in the U.S. have some form of arthritis or arthritis-related disease, including about half of all individuals over the age of 65.[1] These conditions remain the most common cause of disability in the U.S.[2] and often produce deleterious effects on individuals' physical activity, quality of life, and daily functioning.[2]

Self-management programs have been developed and implemented as a means of helping individuals better manage pain and other arthritis-related symptoms.[3] The Arthritis Foundation disseminates a number of evidence-based self-management programs, including the Arthritis Self Help Program (ASHP), a community-based program that improves participants' pain-management abilities by enhancing self-efficacy.[4] The efficacy of the

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ASHP has been studied extensively (although almost exclusively in non-Hispanic white populations), and the program has been found to improve participants' pain and pain-related symptoms.[5] Despite this evidence base, it is estimated that Arthritis Foundation-sponsored programs have reached fewer than 1% of U.S. adults with arthritis or an arthritis-related disease.[6]

A growing body of research indicates that adapting evidence-based programs for use by specific groups can improve their reach and possibly their effectiveness.[7–10] Evidence-based programs are most often adapted when the target population for the intervention differs culturally, geographically, or with respect to risk behaviors or age composition from the population in which the program's effectiveness was established. When used in this way, planned adaptation can balance fidelity to the program's core components while optimizing its fit for the new target population.[11]

The current study sought to effectively implement the ASHP in three senior centers serving predominantly African American, Hispanic, and non-Hispanic white older adults through a collaborative adaptation process. Adapting the program to maximize its utility for older African American and Hispanic populations is appropriate because of established disparities in the management of pain as a function of race or ethnicity[12] and recognized cultural differences in pain management preferences.[13–15] In addition, the ASHP was originally developed and validated in studies of non-older, mostly non-Hispanic white adults with arthritis pain,[3–5] raising the issue of limited "fit" between the ASHP and our target populations. Finally, because the goal of this project was to establish an ongoing program that would outlive the research stage, we undertook a planned adaption of the ASHP (using community-based participatory research methods), so that host sites, program participants, and researchers could collaboratively develop a program that met user needs while retaining the program's core elements.

In this article, we review the adaptation process, present participants' recommendations for modification, and discuss the outcomes of the process (the adapted curriculum) in terms of future sustainability and dissemination of the ASHP to racially diverse urban older adults.

METHODS

We developed a method for program adaptation for use in this project, the Method for Planned Adaptation through Community Engagement (M-PACE), that is described in detail elsewhere.[16] An abbreviated description of the method follows. The essential steps in M-PACE include 1) creating a community steering committee; 2) implementing the unadapted program; 3) gathering feedback about the program and how it could be optimally adapted through multiple data collection methods; and 4) employing a shared decision-making approach that includes community members and content experts to adjudicate all recommendations for program changes.

Creating a Community Steering Committee

The most important step in the adaptation process was the creation of a Steering Committee (SC), a group of 14 content experts and stakeholders who planned and implemented the program adaptation. The SC oversaw all aspects of the adaptation process, including adjudicating and implementing recommendations for change. Community partners included three multi-service senior centers in New York City: 1) a community center serving African American older adults in central Harlem; 2) an agency providing services to older Hispanic residents in the south Bronx; and 3) an agency that serves a mostly older, non-Hispanic white population located in the western part of the Bronx. Additional community partners included a New York City-based elder service agency advocacy organization and the New

York City chapter of the Arthritis Foundation. SC members included staff from the senior centers, older adults with pain problems receiving services from the centers, a staff member from the local chapter of the Arthritis Foundation, ASHP certified instructors, and members of the research team. The SC met at least monthly, with more frequent meetings occurring when needed. The study was approved by the Weill Cornell Medical College Institutional Review Board.

Implementing the Original ASHP in the Three Target Populations

The unadapted ASHP was implemented three times at each center with different groups of participants, consecutively between July, 2008, and March, 2009. All classes were taught by Arthritis Foundation certified instructors. Senior center staff recruited prospective participants who were required to 1) be 60 years of age or older, 2) have a self-identified arthritis or arthritis-related (e.g., back pain) disorder, and 3) be verbally fluent in Spanish or English. All who expressed interest were enrolled in the study, i.e., no one failed to meet the criteria for inclusion. Participants were compensated up to a total of 70 dollars for time spent participating in 6 weekly phone interviews and one focus group as described below.

Brief description of the ASHP—The ASHP consists of 6 weekly group sessions led by an Arthritis Foundation-certified instructor, lasting approximately 2 hours each. There is an English-language[17] and a Spanish-language version;[18] both include core modules on 1) education regarding pain and its consequences, 2) relaxation skills training, 3) cognitive coping skills training, 4) problem solving, and 5) communication skills training. Weekly action plans teach participants goal setting skills and enhance feelings of self-efficacy and support. The English-language program educates participants about the importance of stretching, endurance, and strengthening exercises as a means of maintaining function and managing pain, with encouragement provided during class to practice the exercises at home. The Spanish-language version additionally includes actual practice of the exercises during class. Both programs have participants practice the relaxation techniques during class.

Generating Recommendations for Program Adaptation

Telephone interviews with program participants—Recommendations for program adaptations were solicited from program participants each week, through telephone calls (in English or Spanish) from research assistants, and at the end of the program, through focus groups. Each week, participants were asked, “What did you like most about this week’s class?” and “What did you like least?” Questions were specific to that week’s program module were also included, such as, “Please tell me what you thought about the section of the class that covered healthy eating?” and “Did you find these materials helpful or not?” To raise the issue of cultural adaptation, all groups were asked to “think about people you know who you consider to be like yourself and who experience pain on a regular basis” and talk about why those people would or would not find the week’s class helpful. Finally, African American and Hispanic participants were asked, “As you know, we are looking at how different racial and ethnic groups view this program. Do you see any ways that the last session could be changed to be more interesting or useful to older [Latinos/African Americans]?”

Interviews were audiotape recorded and participants’ responses to the open-ended questions were transcribed in full. Spanish-language interviews were translated into English by bilingual translators with expertise in Spanish to English translation.

Focus groups with program participants—At the end of the program, focus groups were conducted with each ASHP class by research staff (MCR, SP). Three classes were convened at each center for a total of 9 focus groups. A Spanish interpreter was present for

the focus groups conducted with Spanish-speaking participants. Questions posed to all groups included: “What would an ideal pain program look like to you?” and “Do you have additional comments or suggestions about how to improve the program for older adults?” For sites serving predominantly African American and Hispanic clients, the following question was asked: “A lot of researchers and program designers believe we should adapt programs like the one you just took for different cultural groups. Do you agree or disagree with this view? Why or why not?” and “Thinking about the program you just participated in, how do you think it could be changed to best meet the needs of clients at [name of participating center]?”

All focus groups were audiotape recorded and transcribed in full, including translation of Spanish language discussion that took place during the focus groups.

Recommendations from ASHP instructors—Six ASHP instructors taught the classes and were telephoned weekly after each class to generate additional recommendations for program adaptation. Instructors were asked to review each activity completed during that week’s session and comment on the most and least successful aspects of the class. The research team also met with the instructors after all 9 courses had been completed to review their suggestions as a group. All phone interviews and the final meeting were audiotape recorded.

Additional types of data collected—Using a standardized 35-item instrument in English[19] and Spanish,[20] information regarding program participants’ demographic, clinical, and arthritis-related data was obtained by research assistants before the first class.

Data Analysis

All transcribed interview data were entered into nVivo 8[21] and analyzed by two investigators (SJP, DF) to identify specific themes using content analysis.[22] The investigators identified blocks of conversation within each transcript that referenced a specific topic. These conversation blocks were grouped according to theme (e.g., relaxation exercises, eating and diet). All members of the research team reviewed the categorization of text into specific themes, and all disagreements about categorization were resolved through consensus.

Focus group transcripts were read by all members of the research team. One investigator (SP) abstracted recommendations from the transcripts. The research team met to review the abstracted recommendations and confirmed the list of recommendations.

One member of the research team (SP) reviewed the audiotape recordings and summarized the recommendations made by the instructors. The instructors met once at the end of the data collection phase to review the summarized recommendations and confirm the list of recommendations. A final list of instructor recommendations was compiled based on the instructors’ input.

Adopting recommendations—The SC reviewed all feedback from participants and instructors as a group. Program suggestions were evaluated based on congruence with the internal logic of the ASHP, feasibility for instructors and host sites, and perceived importance of each idea. The presence of multiple constituencies and perspectives within the SC (e.g., researchers, senior center program staff, Arthritis Foundation staff) ensured that recommendations for program change were carefully weighed against core components of the evidence-based ASHP. Consensus was required to adopt any changes to the ASHP curriculum. Adopted changes that required more work (i.e., creating a handout on diet and nutrition) were delegated to a sub-committee of the SC who produced these materials.

RESULTS

Characteristics of Study Sample

One hundred twelve adults took the original ASHP course. Participants were older (average age = 75 years), mostly female (83%), reported an average pain intensity score of 4.6 (range, 0–10) at enrollment, and identified as African American (n=37), Hispanic (n=38) or non-Hispanic white (n=37). Fifty-one percent reported having a high school education or less and 58% lived alone. About half (46%) reported osteoarthritis as their cause of pain, other causes included back pain and rheumatoid arthritis, while 65% reported experiencing pain problems for 5 or more years.

Accepted Recommendations for Program Change

Participants made 71 unique recommendations for program adaptation, 37 (54%) of which were accepted. The accepted recommendations reflect both general and group-specific ways that participants felt the program could be changed to make it more applicable, enjoyable, or useful.

Space limits preclude showing all 71 recommendations (which are available upon request from the authors); a subset of 17 recommended changes accepted by the SC appears in Table 1 with a description of how the ASHP was actually modified. Most accepted recommendations centered around: (1) restructuring the class format to maximize learning (e.g., cutting down on individual sharing and distributing an agenda at the start of each class); (2) modifying elements of the program such as simplifying reading materials to accommodate persons with lower literacy levels and expanding or adding topics (e.g., expanding section on healthy eating, adding information on traditional remedies and spirituality); (3) facilitating maintenance of treatment gains (e.g., educating participants about local wellness resources, emphasizing signing up for local exercise or movement courses as part of the action plan activity); and (4) incorporating exercise practice in the English-language program or augmenting the amount of time devoted to exercise practice in the Spanish-language version.

Program instructors made 15 recommendations regarding possible ways to enhance program delivery, 5 of which were also made by the participants. Of the remaining 10 suggestions, 8 were accepted and implemented by the adaptation sub-committee (e.g., move meditation/relaxation technique practice to end of each class). ASHP instructors also generated 33 suggestions for program content change; 20 of these were also made by the senior center clients. Of the 13 recommended changes that were unique to the instructors, the adaptation sub-committee elected to accept and operationalize three: 1) add recommendation to ask participants' doctors about the cause of their pain problem or type of arthritis they have; 2) remove section on evaluating treatments (to make time for added exercises), and 3) add "sleep tips" to Spanish class (already present in the English class).

Recommendations for Program Change That Were Rejected

Of the 34 senior center client recommendations and 12 instructor recommendations not accepted by the committee, most were rejected because of concerns about the feasibility of implementing them. For example, several participants recommended increasing the amount of time devoted to lecture by the instructors, or increasing the scope of the class content. Content experts on the SC felt that these types of expansions were not feasible given the 2 hour time limit of each class. Other participants suggested that the class be offered on a twice-weekly basis. Senior center staff, citing how heavily scheduled their facilities are for other programming, considered this recommendation to be impractical.

Not all suggestions were rejected because of concerns of feasibility. For example, although many participants wanted more exercise practice time in the classes, the SC was careful to weigh this preference against other important components of the ASHP. In the Spanish-language program, which already contained exercise practice, exercise time was actually reduced to accommodate expanding other sections.

Variation in Recommendations by Participant Race or Ethnicity

This program adaptation was undertaken with the suspicion that an evidenced-based program validated in white, non-older adults would benefit from cultural tailoring for urban, racially and ethnically diverse older adults. When looking at the types of program recommendations by race or ethnic group, the questions directed at minority participants regarding how best to culturally modify the program generated few recommendations. Indeed, most African American participants recommended that the program should not be changed based on a person's race or ethnicity. As one participant remarked: "No matter what color you are, if you've got arthritis of the knee, that's going to hurt; it's got nothing to do with color." As another African American participant noted: "As far as I'm concerned we're not different than anybody else; everybody's got problems with the bones, black, white; we all have trouble with our bones after a while." Most Hispanic participants also recommended that no changes were needed for an older Hispanic population.

Cultural differences did emerge, however, in questions that did not specifically address adaptation for racial or ethnic groups. For example, while 29% of African American (and 26% of non-Hispanic white) participants suggested adding physical exercise to the weekly classes, 60% of Hispanic participants made this suggestion. Other differences in endorsement of recommendations between race and ethnic groups were likely due to educational differences between the groups. For example, 20% of Hispanic participants reported problems reading the hand-out materials and arthritis book versus 13% of African Americans but only 6% of non-Hispanic whites.

DISCUSSION

Our study extends prior research[23–27] by demonstrating the value of CBPR as an effective method for adapting an evidence-based, self-management pain program for use by three groups of older adults attending senior centers in New York City. Adaptations occurred in several discrete areas including: 1) restructuring the class format to maximize learning; 2) modifying program elements to accommodate persons with lower literacy levels; 3) expanding existing or adding new educational components; and 4) adding mechanisms to enhance the likelihood that participants use the techniques learned in class over time.

This process helped to create an adapted program whose reach and effectiveness may be superior to the original ASHP. For example, our results demonstrated that a substantial minority of Hispanic participants had difficulty with the reading materials. This finding led the SC to incorporate low-literacy reading materials for future use at the senior center serving Hispanics and an intake assessment designed to help instructors understand the literacy level of ASHP participants and adapt program materials accordingly. African American and non-Hispanic white participants felt the program could be improved by including actual practice of the physical exercises during class. This recommendation was adopted and may help to increase adoption of the physical exercises as a means of managing pain in these two target groups. Finally, participants felt strongly that one way to help attendees continue to use the exercises learned in class was to join an ongoing exercise program, e.g., walking club, tai chi class at their respective center or at other nearby locations. The SC accepted this recommendation and created an 'action plan for sustainability' that encouraged participants to join one or more of these ongoing classes after

completing the ASHP program. This change could possibly help to maintain treatment gains over time, which has been a problem with behavioral interventions in general.[28–30]

This study also adds to the limited literature regarding specific approaches used to adapt evidence-based programs for use by distinct cultural groups. Some cultural preferences emerged, e.g., African Americans were more likely to endorse adding a component on spirituality as a means of managing pain, while Hispanic participants advocated for augmenting the section on physical exercise, and non-Hispanic whites were more likely to recommend shortening the individual sharing section of each class. These differences emerged during routine questions about participants' likes and dislikes of each week's class and not by asking whether specific program changes should occur for each race or ethnicity group. This finding suggests that questions that ask how the program should be changed to best meet the needs of "similar individuals" or "individuals belonging to one's own race or ethnic group" are not likely to pay dividends, particularly among older African American and Hispanic populations. Future research is needed to determine the types of questions that can best elicit recommendations for program change based on an individual's race or ethnicity.

Charging the SC with the task of adjudicating all recommendations and deciding how to implement the accepted recommendations for change into the ASHP curriculum served two important functions. First, the SC balanced the recommendations of participants and instructors against the essential features of the evidence-based intervention. Second, because instructors and staff from the host sites served on the SC, recommendations were rejected if they were outside of the bounds of what they felt their agencies could implement. Community-based health promotion programs could be adapted with extensive participant feedback or sound theoretical reasoning but still have poor fit or low impact if they fail to meet the needs of the practitioners and agencies that administer them. Program recommendations made by participants and instructors tell us about contextual differences or desires in the target population. Equally telling are the types of suggestions that were deemed not feasible by the SC; host sites face very real constraints that must be honored in order for programs to be sustained.

This study has several limitations that warrant consideration. The specific adaptations adopted in this study may not be generalizable to other populations, community settings, or community-based health interventions, although the *process* of program adaptation could be used in many different contexts. Second, the adaptation method used here assumes that participants and instructors of an intervention can generate high-quality recommendations for program change. Researchers in the CBPR tradition would assert that collaboration with (versus without) communities often leads to better results, but critics of our method might question the ability of program participants' likes and dislikes to effectively guide the adaptation process.

In conclusion, our results demonstrate the value of CBPR as an effective tool for adapting an evidence-based arthritis self-management program for use by racially and ethnic diverse groups of older adults. Our findings highlight the way that collaboration with community partners can promote tailored programs that are feasible for the host sites, thereby increasing the likelihood of sustaining the programs over time. Further research is planned to determine whether the adapted (versus original) ASHP program produces similar (or superior) outcomes when implemented in senior centers serving older African American, Hispanic or non-Hispanic older adults.

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Table 1

Examples of Recommendations Accepted by the Steering Committee and Actions Taken to Operationalize Each Recommendation

	Action(s) Taken
Improve and provide additional guidance/training on class facilitation	
Customize class to education level of group	• Included "low literacy guide" for Spanish-language version of class • Included hand outs with more in-depth resources
Add component about sharing helpful pain techniques	• Emphasized brainstorming activity on how participants use distraction techniques to manage pain
Provide information on other pain management resources	• Created "other resources" hand out with information on pain management books, websites, CDs and organizations
Add exercise component	
Add exercise to class	• Added in-class exercise practice to English-language version
Modify program to accommodate varying literacy levels	
Modify class materials to accommodate participants with lower literacy	• Added intake survey with literacy-related questions to inform instructors about literacy level of participants • Added extra resources for both lower and higher literacy groups • Created pre-written hand outs to replace course sections requiring extensive writing (e.g., writing a letter to your doctor)
Provide additional attention to diet and nutrition	
Expand section on healthy eating	• Added information on a healthy plate and food pyramid
Add component on complementary/alternative pain approaches	
Add section on folk or traditional remedies	• Added time for discussion of these methods
Add section on spirituality as method of dealing with pain	• Added spirituality to list of coping mechanisms
Enhance and expand partnering component	
Have buddies schedule specific time to call one another	• Added recommendation to have buddies call one another at specific time of day
Enhance meditation and relaxation components	
Provide relaxation/meditation tapes	• Added tapes to English course (already part of Spanish course)
Hand out guided imagery scripts or provide recommendations where participants can get them	• Created list of resources to distribute during class as a hand out
Add component about use of music as a distraction/relaxation technique	• Added music to meditation component
Promote individual sustainability	
Encourage journaling after course is over	• Added action plan hand out to promote journaling
Use calendar reminders as a tool to facilitate continued use of exercises taught in class and maintain program gains	• Added recommendation to write down activities in calendar

	Action(s) Taken
Educate participants about local exercise/disease self-management programs in neighborhood	• Created “action plan for sustainability” to link participants with exercise/disease self-management programs in neighborhood
Other recommendations	
Spend more time on cognitive techniques	• Added brief mediation session at end of each class • Added meditation CD hand out to English version • Added a brainstorming activity on helpful cognitive techniques
Add component on additional types of pain	• Added information on other pain types