Editorial

Patient Self-Management in Arthritis? Yes!







Nearly 2 decades ago a new treatment modality was proposed as an important therapeutic adjunct for patients with arthritis: self-management¹. An underlying premise was that absent the help of the patient, optimal chronic disease outcomes could not be attained. The choice of the term "self-management" was deliberate and is important. It is not "self-care," although it includes this domain, because it also includes making appropriate use of professional medical care. It is not "patient education" in the traditional sense, since it is directed at changes in health status and appropriate health care utilization rather than an accumulation of knowledge and to a lesser extent behavior change.

The new treatment modality was effective¹⁻³. It reduced pain, sometimes reduced disability, improved fatigue, and reduced utilization of medical services. It was effective for at least 4 years. Effectiveness was documented by a number of well controlled studies by multiple groups in different settings with different ethnic groups and in different countries⁴⁻¹¹. The Arthritis Self-Management Program (ASMP) was endorsed and recommended by the US Centers for Disease Control, the Arthritis Foundation, and the American College of Rheumatology (ACR)^{11,12}. It has led to similar efforts in other areas of medicine, such as pain, back pain, and a generic chronic disease course¹³⁻¹⁸.

The mechanism of action of a new treatment is always of interest, and often not certain. The ASMP was originally expected to work through: (1) Encouraging exercise, use of nonpharmacologic pain-management techniques, and through specific resource recommendations, exercise prescriptions, relaxation techniques, cognitive distraction, use of aids and devices, and action plans¹⁹. (2) Use of a series of 6 weekly 2-hour interactive seminars with 2 trained lay leaders, at least one of whom had arthritis and could serve as a role model for participants.

A third mechanism of action, improvement in personal perceived self-efficacy, subsequently proved to be perhaps

the most important. Improvement of the patient's confidence that they can manage the consequences of their arthritis enabled the person to actively seek and implement solutions. As an explanatory variable, perceived self-efficacy explained more of the variance in outcomes than any other variable^{20,21}. Most of the more than a dozen studies of the ASMP model over the past 15 years of which we are aware have been positive, except for one²². This is extraordinarily reassuring, since concerns about maintaining high leader quality in relatively unsupervised settings have always been present.

The single dissenting study²² thus requires critical dissection. This study, by Solomon and colleagues in a recent issue of this journal, attempted to evaluate the ASMP course in patients recruited from a primary care physician network in a "randomized control" study, and concluded that the program was not effective in such a setting. This would be a serious conclusion, since it would imply that ASMP-type courses should not be given to primary care patients. Leaving aside caveats such as that this was a single network with a single trainer and that other primary care patient populations such as those in the Kaiser Permanente system have been found to improve with these interventions, there are serious and unsettling flaws in their study design and execution²³.

First, this was not a randomized trial, despite the misleading use of this term in the title. The authors randomized 12 sites into 2 groups of 6; patients were not randomized. It is of course permissible to use groups as the unit of randomization, but use of only an "n" of 6 is inadequate to ensure balanced groups. Then, when recruitment into the course lagged, they transferred a large control site into the intervention arm! Thus, this is not a randomized trial, and the unbalanced treatment groups further document this. The intervention group had about half the number of patients with rheumatoid arthritis (RA), was 7 years older, was more

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numerous, less educated, and less affluent. In all, 6 of 20 baseline variables differed significantly between groups; such differences would be highly unlikely in a truly randomized study. The effect of this imbalance is hard to predict, but it suggests the likelihood of other, unmeasured, major differences between groups as well as those reported.

Second, Solomon, et al used an active control, The Arthritis Helpbook²⁴, in the control group, which may have had the result of lowering between-group differences. Most prior work has either used questionnaire-only controls or has used information-only controls such as Arthritis Foundation pamphlets, in order to minimize the likelihood that the control group would have been given an active intervention. The Helpbook is the major resource of the ASMP course, and is aimed directly at the identical goals of behavior change and self-efficacy improvement as the group interactions of the course. Solomon, et al had, as they acknowledge, great difficulty in patient recruitment and retention. Only 12% agreed to participate. Only 50 and 62% of the intervention and control groups, respectively, completed the study. Of those characterized as study "completers," only 84% actually had actually completed two-thirds of the course.

Additionally, there may have been a problem with study design and data collection. In previous studies, even in large health plans, the study completion rate is usually above 80%. With the very high dropout rate in the Solomon study it is difficult to draw any conclusions about the intervention. A final problem involves the actual delivery of the ASMP, which was designed to be delivered by a pair of lay leaders, at least one of whom had arthritis and thus could serve as a role model for the participants. From the article it appears that there was only one leader who was sometimes "assisted" by someone with arthritis. Based on this and some of the content that was listed that is not in the ASMP protocol, there are questions about the fidelity of delivery of the intervention.

On its face, one would not expect patients in one kind of practice or another to be more or less responsive to a self-management program, particularly when the physicians are not involved in the study, which selects subjects by diagnostic codes from an administrative database. We find it curious that Solomon, *et al* selected the "practice setting" explanation for their results, which goes against prior literature, as opposed to discussing recruitment bias, lack of randomization and resulting imbalances between groups, possible ineffective program delivery, effects of having an active control intervention, or high dropout rates, which we suggest are far more likely.

Granting the success of the ASMP program and the repeated documentation of its effectiveness in many settings, why have only a small minority of persons with arthritis actually taken the course? A large issue is access to the course because of logistical problems, with courses

offered generally once or twice a year in a metropolitan area at locations unavoidably inconvenient for many. There is an accompanying capacity issue, where the number of lay leaders that would be required to lead small groups for many millions of persons with arthritis is immense. There are 3 approaches to these problems, which together may take arthritis self-management into the next era.

First, by systematically placing self-management programs within health care delivery systems, and repeating offerings over several years, there is growing evidence of increased patient participation. While initial enrollments may be only 10 or 15% of those eligible, with regular offerings participation rates increase markedly. Such systemwide implementation of our Chronic Disease Self-Management Program (ASMP's sister program) is now being undertaken by the Kaiser Permanente System, Health Insurance Plan of New York, Health Care Cooperative of Puget Sound, the National Health Service of England, and more than 100 other health care organizations^{23,25}. Patient education is recommended by the ACR for osteoarthritis of the hip and knee²⁶.

Second, there is now a mail-based program termed "SMART" (Self-Management Arthritis Relief Therapy) that provides the same approach to improved self-efficacy and behavior change as the ASMP. It uses a computer-supported "tailored print intervention" with a series of interactive questionnaires and responses enabling very personalized recommendations. The program includes the Helpbook. This intervention has been studied in 3 truly randomized trials including managed care, rheumatologist patients, and primary care patients, with major effectiveness documented^{27,28}. Results have been similar to those with the ASMP course, with the increased specificity of recommendations offsetting the loss of extensive person-to-person interaction. A mail-delivered program allows access to any person at any time. Computer-based algorithms and operations permit applications of essentially any size.

Third, we are developing, with National Institutes of Health support, a Web-based ASMP program embodying the same principles and materials. Features include an interactive "learning center" where participants can learn self-management techniques, a "communications center" where participants and leaders can interact by use of bulletin boards and e-mail, and a personal "my stuff center" where participants can keep progress logs, journals, and medication records. Preliminary Web applications in low back pain and in generic chronic disease suggest that these efforts are likely to be effective.

Increased patient self-management of chronic illness is essential to improved patient outcomes. The magnitude of effect of such interventions in arthritis is similar to that of nonsteroidal antiinflammatory drugs, with rather less gastropathy, and with effects that are additive to those of medical treatment. Yet these interventions remain unfamiliar

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to many and poorly understood by others. It is time for broader dissemination, and that will require efforts from all of us.

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REFERENCES

- Lorig K, Lubeck D, Kraines R, Seleznick M, Holman H. Outcomes of self-help education for patients with arthritis. Arthritis Rheum 1985;28:680-5.
- Lorig K, Holman H. Long-term outcomes of an arthritis self-management study: effects of reinforcement efforts. Soc Sci Med 1989;29:221-4.
- Lorig K, Mazonson P, Holman H. Evidence suggesting that health education for self-management in patients with chronic arthritis has sustained health benefits while reducing health care costs. Arthritis Rheum 1993;36:439-46.
- Lorig K, González V, Ritter P. Community-based Spanish language arthritis education program. A randomized trial. Med Care 1999;37:957-63.
- Barlow J, Turner A, Wright C. Long-term outcomes of an arthritis self-management programme. Br J Rheumatol 1998;37:1315-9.
- Barlow J, Turner A, Wright C. A randomized controlled study of the arthritis self-management programme in the UK. Health Educ Res 2000;15:665-80.
- Barlow J, Williams B, Wright C. Patient education for people with arthritis in rural communities: the UK experience. Patient Educ Couns 2001;44:205-14.
- Chui D, Poon P, Lee E, Lau J. Self-management programme for rheumatoid arthritis in Hong Kong. Br J Therapy Rehab 1998;5:477-81.
- Goeppinger J, Arthur M, Baglioni AJ, Brunk S, Brunner C. A reexamination of the effectiveness of self-care education for persons with arthritis. Arthritis Rheum 1989;32:706-16.
- Lorig K, Laurin J, Holman H. Arthritis self-management: a study of the effectiveness of patient education for the elderly. Gerontologist 1984;24:455-7.
- McGowan P, Green L. Arthritis self-management in native populations of British Columbia: an application of health promotion and participatory research principles in chronic disease control. Can J Aging 1995;14:201-12.

- US Department of Health and Human Services. Health people 2010. Conference edition in 2 volumes. Washington, DC: US Department of Health and Human Services; 2000.
- Lorig K, Gonzalez V. Community-based diabetes self-management education: definition and case study. Diabetes Spectrum 2000:13:234-8.
- 14. Lorig K, Ritter P, Stewart A, et al. Chronic disease self-management program. 2-year health status and health care utilization outcomes. Med Care 2001;39:1217-23.
- Lorig K, Sobel D, Stewart A, et al. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. Med Care 1999;37:5-14.
- Von Korff M, Moore J, Lorig K, et al. A randomized trial of a lay person-led self-management group intervention for back pain patients in primary care. Spine 1998;23:2608-15.
- McColl G. Efficacy of the arthritis self-management course in Australia. Aust NZ J Med 2000;30:527-34.
- LeFort S, Gray-Donald K, Rowat K, Jeans M. Randomized controlled trial of a community-based psychoeducation program for the self-management of chronic pain. Pain 1998;74:297-306.
- Lorig K. The arthritis self-help workshop. Leader's manual. Stanford, CA: Stanford University; 2001.
- Lorig K, Seleznick M, Lubeck D, Ung E, Chastain R, Holman H.
 The beneficial outcomes of the arthritis self-management course are not adequately explained by behavior change. Arthritis Rheum 1989;32:91-5.
- Lorig K, Ung E, Chastain R, Shoor S, Holman H. Development and evaluation of a scale to measure perceived self-efficacy in people with arthritis. Arthritis Rheum 1989;32:37-44.
- Solomon D, Warsi A, Brown-Stevenson T, et al. Does self-management education benefit all populations with arthritis? A randomized controlled trial in a primary care physician network. J Rheumatol 2002;29:362-8.
- Lorig K, Sobel D, Ritter P, Laurent D, Hobbs M. Effect of a self-management program on patients with chronic disease. Eff Clin Pract 2001;4:256-62.
- Lorig K, Fries JF, Gecht MR. The arthritis helpbook: A tested self-management program for coping with arthritis and fibromyalgia. Cambridge, MA: Perseus Publishing; 2000.
- Department of Health. The expert patient: a new approach to chronic disease management for the 21st century. National Health Service of England: London, England. [Cited December 9, 2002] Available from: http://www.doh.gov.uk/cmo/ep-report.pdf
- American College of Rheumatology Subcommittee on Osteoarthritis Guidelines. Recommendations for the medical management of osteoarthritis of the hip and knee. Arthritis Rheum 2000;43:1905-15.
- Gale FM, Kirk JC. Patient education and self-management; randomized study of effects on health status of a mail-delivered program [abstract]. Arthritis Rheum 1994;37 Suppl:S197.
- Fries JF, Carey C, McShane DJ. Patient education in arthritis: randomized controlled trial of a mail-delivered program.
 J Rheumatol 1997;24:1378-83.