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# Arthritis Care: Comparison of Physicians' and Patients' Views

Bruce L. Lambert, Ph.D.
Associate Professor
Department of Pharmacy Administration
Department of Pharmacy Practice
University of Illinois at Chicago

Danielle N. Butin, MPH, OTR
Clinical Instructor, Occupational Therapy
Columbia University
and
Manager, Health Promotion and Wellness Department
Oxford Health Plans

Diane Moran, R.N., M.A., Ed.M. National Director, Managed Care G. D. Searle & Co., Skokie, IL

Sean Z. Zhao, M.D., PhD. Associate Director, Arthritis Team G. D. Searle & Co., Skokie, IL

Barbara C. Carr, M.S.
Adjunct Professor
Program in Health Science/Exercise Physiology
Long Island University
and
Program Manager, Medicare Health Promotion Department
Oxford Health Plans

Connie Chen, Pharm.D.<sup>d</sup> Manager, Arthritis Team G. D. Searle & Co., Skokie, IL

> F. J. Kizis, M.S. Data Analyst Oxford Health Plans

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Address: Department of Pharmacy Administration,

833 S. Wood Street (M/C 871), Chicago, IL 60612-7231

 Phone:
 312-996-2411

 Fax:
 312-996-0868

 Email:
 lambertb@uic.edu

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Comparative Views of Arthritis Care

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## **Abstract**

**Objectives.** To understand the expressed needs of physicians and their patients with respect to arthritis care, identify areas of agreement and disagreement in doctor and patient views of arthritis care, and to determine the types of educational programs needed.

**Methods.** Focus group interviews were conducted with 14 physicians of varied specialties and 12 patients with arthritis from Oxford Health Plans. Interviews were audiotaped and transcribed. Analyses were carried out using text processing programs from the Unix<sup>®</sup> computer operating system. Common themes were identified and summarized.

**Results.** Physicians and patients agreed that pain and loss of functioning were the most important problems patients with arthritis faced and that arthritis was incurable. Both agreed that doctors need more time to discuss individual concerns with their patients. More information about diet and exercise and strategies for reducing social isolation were needed. Doctors and patients disagreed about the value of nutritional supplements, joint replacement, and referrals to specialists. Disagreement also existed regarding the belief that pain was an inevitable part of the aging process, and with respect to the use of drug and surgical therapy.

Conclusions. Areas of agreement and disagreement were discussed. Collaboration and negotiation were identified as constructive responses to conflicts between physicians and patients. Patients need to be taught self-care strategies in order to minimize the impact of arthritis on their daily lives. The specific continuing education needs of physicians involved training in exercise, nutrition, occupational and physical therapy prescriptions and alternative medicine

Key Words: arthritis, focus group, doctors, patients, patient education, self-care preferences, beliefs

## Introduction

Arthritis is a painful, disabling, chronic disease of the joints and connective tissues. There are nearly 354 million persons with arthritis worldwide including over 40 million in the US.<sup>1, 2</sup> Arthritis costs the US economy roughly \$65 billion per year in health care expenditures and lost productivity.<sup>2</sup> One in ten visits to office-based physicians is for arthritis care, making arthritis the second most common chronic condition seen in ambulatory care settings.<sup>3</sup> In 1996, patients seeking care for arthritis made more than 77 million visits to office-based physicians.<sup>3</sup> Thus, a thorough understanding of patient perceptions of arthritis and arthritis care is vital to practitioners to best meet the educational needs of the patient and provide optimal arthritis care.

Patient education has been shown to improve the quality of life among patients with arthritis. According to Lorig and Visser, patient education is defined as "planned, organized learning experiences designed to facilitate voluntary adoption of behaviors or beliefs conducive to health." Widely adopted standards for arthritis patient education require providers to do a needs assessment before designing an educational program for a particular group. The decision to mandate a needs assessment before designing an educational program for patients with arthritis is also consistent with a patient-centered approach to medical care. Care is said to be patient-centered when treatments are tailored to fit the needs, beliefs, and preferences of individual patients. This requirement recognizes that arthritis is a complex and variable set of conditions, the effects of which vary considerably as a function of arthritis type, disease severity, and patient psychosocial and demographic characteristics. Focus group interviews are an ideal way to elicit the educational needs of patients.

Once the educational need has been ascertained, challenges may arise when attempting to deliver patient-centered education. Physicians and patients often have conflicting needs, beliefs and preferences about care. 9-13 This conflict is not new, nor is it unique to arthritis. 13-18 In general, physicians' goals tend to be grounded in a biomedical understanding of disease. Consistent with their medical training, doctors are concerned with diagnostic tests to determine levels of biological markers, and clinical

management of visible symptoms and signs of disease. These goals are often described to patients in abstract, technical, biomedical terms. <sup>16</sup> Patients' goals, in contrast, tend to be grounded in subjective experience, information gleaned from lay referral networks, and folk theories of illness causation and treatment. <sup>19</sup> Rather than focusing on biomedical goals that are distant in time (e.g., reduction of long-term risk) patients are apt to focus on short-term quality of life concerns. Often, these priorities can only be understood in relation to an individual patient's personal and social identity. <sup>20–22</sup> It is important for the physician to be aware of these differences in perspective in order to provide optimal care. <sup>5</sup>

In spite of evidence to the contrary, many medical interactions continue to be based on the assumption that doctors and patients share a common goal or set of goals. <sup>15</sup> In some sense, this may be true. But in a more practical sense, the assumption of common goals may not be valid. In fact, this assumption may actually be harmful. Doctors and patients who assume common worldviews, vocabularies, and goals may be surprised and unprepared to deal with conflict. <sup>15</sup> This lack of readiness to deal constructively with manageable conflict manifests in both overt and covert actions that undermine the effectiveness of doctor-patient collaboration. <sup>23</sup>, <sup>24</sup> Overt conflict undermines trust, damages the empathic connection between doctors and patients, and can result in doctors asserting power or retreating into technical justifications for decisions not arrived at jointly. Patients who shy from the inevitable conflict may reassert their own autonomy outside the clinic by covertly refusing to adhere to recommended treatment regimens. <sup>15</sup> In either case, failure to acknowledge and deal with conflict jeopardizes quality care, especially in chronic conditions where the achievement of quality of life goals almost always depends on negotiated adherence to long-term regimens. <sup>9</sup>, <sup>25</sup>

The present study was undertaken as part of an ongoing effort to understand the needs of physicians and patients in regards to arthritis care. The findings would aid in the effort to produce and deliver quality arthritis education. In order to make these educational interventions as sensitive as possible to the needs, beliefs, and preferences of the individuals involved, the opinions of selected doctors and patients were elicited in small group interviews. The purpose of the study was to identify the views of older patients with respect to arthritis care, identify the views of physicians with respect to arthritis care, and to

identify areas of agreement and disagreement between doctors and patients. This information aided the development of patient-centered educational interventions to be used by physicians. Also, educational needs of physicians were identified.

## Methods

Four focus groups were conducted, two with patients and two with physicians. A total of 14 physicians participated in two focus groups. Oxford Health Plan selected physicians from two major areas of New York who they thought would be interested in participating. Their average years in practice was 15 years with a range of six to thirty years (data not available on six physicians). The specialties that were represented included family practice, internal medical, family practice, gastorenterology, rheumatology, and ophthalmology. Twelve patients with arthritis comprised the remaining two focus groups. Limited information was available about the patients. Demographic data from one group was lost entirely in a computer malfunction. For the other group, only age and gender data were available. That group included two men and three women, ranging in age from 70 to 80. The sixth member of this group did not provide any demographic information. All patients had arthritis and, as evidenced by their comments during the group interviews, had been seen by a variety of primary care doctors, rheumatologists, internists, physical and occupational therapists, and pain specialists. The groups were moderated by the manager of the health promotion department at Oxford Health Plan, an occupational therapist who was also an experienced patient educator. All patients with arthritis within the same geographical region were sent an invite to participate in the focus group. Based on responses and follow-up confirmation calls, 12 patients were selected to participate. The questions posed to patients and physicians are shown in Table 1 and Table 2, respectively.

The focus group interview method was used to elicit needs, beliefs, attitudes, norms, and preferences about arthritis care from separate groups of doctors and patients with arthritis from a large managed care organization. When using this method, a moderator leads a focused discussion about a topic of mutual interest to group members. The moderator guides discussion with a prepared set of openended questions and follow-up probes. The focus group method yields feedback in the form of

contextualized, personal opinions and experiences, expressed in everyday language. The data can be used to design programs which can improve a patient's quality of life, to change organizations, affect public policy, change attitudes and behavior and improve quality of care. <sup>26</sup>, <sup>27</sup>

## **Data Analysis**

The same methods were used to analyze both the physician and the patient focus groups. Group interviews were audiotaped and transcribed to computer-readable text. Transcripts were then segmented into independent clauses and then grouped into thematic categories utilizing computer-assisted content analysis. Two basic types of computer-assisted content analysis were used. The first part of the analysis used a document clustering system to group similar independent clauses together into themes. Details of the document clustering method are described elsewhere. This analysis revealed a variety of low-level micro-themes, which were aggregated into macro-themes by the authors. In addition to this analysis, text-filtering tools from the Unix® operating system were used to identify clauses containing a particular word or phrase (i.e., 'medication', 'pain', etc.). Quotations and themes identified in this manner were used to illustrate patient views, physician views, and to highlight areas of agreement and disagreement with regard to the "text-filtered" selected words or phrases

## Results

#### **Patients' Views**

A summary of patients' views is presented in Table 1. Patient perceptions of arthritis as a disease can be understood through statements on how arthritis manifests itself in the lives of patients. Arthritis is expressed primarily as pervasive and persistent pain. Patients perceived this pain to result from a process of erosion and deterioration.

Patient perceptions of what causes arthritis varied greatly. Patient theories about what caused arthritis ranged from physical injuries to viral infections. One patient indicated that the disease was due to a pair of uncomfortable shoes they wore, while another patient stated that arthritis was a "viral infection that goes into the bones, a bacteria of some kind that goes in the bones." The effect of arthritis on patients'

lives could be seen on a physical and mental level. Physical limitations restricted their normal activity resulting in social withdrawal. Also, patients became dependent on others to perform activities they used to be able to do on their own. Relationships with family members suffered. One patient stated that the pain "Gets in your head sometimes," making one so annoyed that it was difficult to carry on a conversation.

When patients were questioned regarding their medical treatment they appeared to be fairly satisfied with the technical and interpersonal skills of their doctors, but they had modest expectations about what medical interventions could achieve. Comments indicated that patients thought the situation was futile. For example, patient quotes included: "That's it, there's really nothing they can do. They cannot play God" and "I think if there was anything more that he could do for it, he would." Patients did voice a common complaint about waiting times and how doctors were extremely busy. One patient commented that physicians did not have the time and had "too many people one after another." To these patients, a good doctor was one who was available whenever a patient called took the patient's pain seriously, and was willing to give referrals to specialists.

Patient perceptions of non-pharmacological therapy indicated that most patients believed in its usefulness, however, they were unsure of how to use it. Patients were fairly uniform in their belief that exercise was good for arthritis pain and stiffness, however, they voiced concerns about the 'right' kind of exercise. Fears about making their condition worse by doing the 'wrong' kind of exercise prevented many patients from exercising at all. Some patients failed to exercise due to perceived inconvenience, while others found exercise to be a helpful way of getting their minds off the pain.

Patients believed that arthritis pain could be minimized by proper diet and nutrition. It was not clear whether these beliefs came from the media, from patients' own experiences or both. The origin of these beliefs is an important topic for future research, as it has implications for subsequent educational outreach efforts. Patients were aware that increases in weight could exacerbate their condition. Many foods, such as red meat and junk food, were believed to exacerbate arthritis pain, while vegetables, bran, and chicken were foods thought to help the disease. Nutritional and herbal products as well as weight loss

were strategies some patients thought were important in reducing the pain from arthritis. The patients who tried these strategies admitted to not informing their physicians in fear of disapproval.

The patients interviewed perceived arthritis to make their activities of daily living difficult, painful, and sometimes impossible. Patients stated that they could not perform or had difficulty performing duties such as housework, showering, bending, walking long distances, or climbing stairs. Despite complaints of functional limitations, none of the patients in the focus group had been referred to occupational therapy.

Sleep was also a problem for these patients, many of whom reported difficulty falling and/or staying asleep. Some patients were not able to have more than a few hours of sleep without being awakened by the excruciating pain. The cycle of sleep, pain, and medication could continue throughout the night with awakened family members affected as well.

The pain of arthritis made sex uncomfortable for most patients causing both patient and spouse to be frustrated. Unwillingness to have sex was said to cause problems in patients' relationships. One patient sarcastically said that she had told her husband "here I'll give you the money, go out and get some."

## Physicians' Views

A summary of physicians' perspectives on arthritis care appears in Table 2. Physicians' responses fell into 8 categories, corresponding to the main questions that were used to guide discussion: training, joint injections, referrals, patients' priorities, nutrition, occupational and physical therapy, continuing education, and sources of frustration.

The physicians we interviewed did not feel well prepared in rheumatology. One doctor responded that "rheumatology was just sort of adjacent to but not quite part of real medicine." Another physician commented that though their training is little to none, nearly 50% of patients have complaints of arthritic problems. Physicians also did not feel comfortable performing joint injections with lack of training cited as the primary reason. Other physicians indicated no interest.

Physicians reported referring to specialists (rheumatologists and pain specialists) when pain was unbearable, when patients insisted, when small joint injections were required or when they felt they had exhausted all of their available treatment options. There was, however, skepticism about the value and effectiveness of pain specialists. One physician stated that pain specialists really are not able to do much for the patient short of placing an epidural to control the pain. Some physicians thought referrals were effective primarily because they made patients feel important. In fact, one physician commented "Just the fact that somebody sent them to a specialist makes them feel better."

There was broad consensus among the doctors that diet (i.e., weight loss) and exercise were both effective interventions. However, several practical difficulties prevented doctors and patients from following through on these sorts of recommendations. Statements from physicians indicated that though the patient needed to exercise and lose weight, it was difficult when patients had arthritis of the knee or back. One physician stated that "It's very hard to lose weight without exercise, and it's very hard to exercise when you can't walk." The difficulty in recommending exercise is also due to other comorbid conditions. When patients have diseases such as coronary artery disease or significant pulmonary disease, additional factors have to be taken into consideration before recommending an exercise program.

Physicians felt they were not qualified to prescribe exercises or nutritional suggestions as they only had minimal studies in these areas in medical school. Furthermore, physicians were uncertain as to where to refer their patients for appropriate exercise programs (e.g. exercise physiologist, physical therapy, gym).

Opinions about occupational and physical therapy (OT/PT) were mixed. Some physicians believed in the potential benefit of OT and PT, but only if programs were run by trained professionals with clearly defined treatment goals that were communicated clearly to the physician. One physician responded "I have no idea what to write on a physical therapy prescription." For the physicians who did use occupational and physical therapy services, they reported needing more education in how rehabilitation directly impacts arthritis. Another physician stated that occupational therapy is beneficial when it is provided in a one-to-one setting and saw little benefit to large group treatment sessions. Physicians were also unaware of the role and benefit of exercise physiologists.

In regard to arthritis care, the physicians we interviewed were frustrated by protocols required by managed care companies, by patients' perceived inability or unwillingness to accept pain, immobility, and loss of functioning as a "natural part of aging". Physicians stated that it was hard to tell patients who had been healthy most of their lives that arthritis was part of aging. The patients "don't want to believe they're sick" and did not think that they should have to accept pain at all. One physician stated that doctors believed that patients had "unrealistic expectations" regarding their arthritis prognosis.

## **Areas of Agreement and Disagreement**

A comparison of doctors' and patients' views reveals several areas of agreement and disagreement. Table 3 lists points of agreement and Table 4 lists points of disagreement. Both parties agreed that pain, immobility, and loss of functioning were the primary problems faced by patients with arthritis. There was also agreement that arthritis was a chronic, incurable condition and that doctors need more time to meet the needs of patients with arthritis. Both doctors and patients need more information about exercise, nutrition, occupational and physical therapy and alternative medicine. Doctors and patients agreed that arthritis suffering could often be managed non-medically by having patients engage in activities that reduced social isolation and distracted them from the pain. It was also agreed that allowing the patient to talk openly about the pain was helpful. There were disagreements between physicians and patients regarding the value of various types of medications, referrals to specialists, use of alternative medicine and expectations for pain relief. Physicians and patients also disagreed on the use of invasive treatments such as surgery and the value of diagnostic procedures.

## Limitations

Results presented here must be interpreted in light of several limitations in the study's methods. Most significantly, the focus group method did not allow results to be generalized to a larger population of doctors or patients. The views expressed by the participants in these discussions may or may not have been representative of those held by the wider group of doctors and patients with arthritis. Some selection bias was probably evident. Doctors who participated were likely to be the more open-minded and better trained than those who did not. Similarly, patients who agreed to participate may have been systematically

different from patients who declined to participate. In addition, doctors and patients were not asked precisely the same questions, a fact that may have tended to minimize points of agreement and exaggerate points of disagreement. Finally, the presentation of qualitative data necessarily involves a process of selection and summarization. Although every effort was made to provide a balanced and comprehensive view of what was discussed in the group interviews, in the final analysis the authors, rather than doctors and patients, decided what points to present and how to present them.

## **Discussion and Conclusion**

A series of focus group interviews with patients with arthritis and physicians provided insight into how each group thought about arthritis care and, in the process, revealed substantial areas of agreement and disagreement. These findings are consistent with others who have compared doctor and patient views in the context of arthritis. 9-12 Identification of these areas of agreement and disagreement may assist in the development patient-centered educational interventions. Such interventions involve the participation of patients and physicians working together in order to the bring biomedical world of the physician and the social world of the patient together to provide optimal care. The increasing involvement of patients in their own health care has become evident through the measurement of outcomes from the patient perspective (e.g. through the use of patient satisfaction surveys and health-related quality of life instruments). 6

What emerged from the analysis of these focus groups was the impression that doctors and patients shared some common ground, but that major areas of disagreement still existed. The common ground is the foundation for further progress. The areas of disagreement represent opportunities for improvement. Points of agreement between physicians and patients indicated that they both viewed arthritis as a condition that significantly contributed to pain and suffering. The loss of social and physical functioning are considered major obstacles associated with arthritis. Literature confirms that pain itself is unwelcome, but more intense suffering resulted when pain led to functional limitations that prevented patients from engaging in valued activities. 29-32 With these aspects of patients' lives being affected, it will be important for physicians to examine the effect of arthritis treatments on health-related quality of life in

order to select therapies with maximal benefit. For example, occupational therapy could have a significant impact on functional status, independence and overall quality of life.

Interviews indicated that doctors and patients occasionally had conflicting needs, beliefs and preferences. For example, patients tended to value low-tech, quasi-medical, and/or alternative treatments (e.g., nutritional supplements) more than doctors. In contrast, physicians tended to favor high-tech, medical and surgical options such as joint replacement. This disagreement is symbolic of larger differences in perspective and priorities. Patients preferred vitamins and nutritional supplements because they were inexpensive, accessible, and manageable within a self-care framework. Vitamins and supplements were also perceived to be comparatively painless, safe, non-intrusive and "good for you". Physicians saw the value in some high-tech interventions (e.g., joint replacement), when the potential benefit was great enough. These same interventions were seen by patients as intrusive, hazardous and posed greater risk. The literature on chronic illness has repeatedly documented a similar pattern of differences: patients pursue personal quality of life goals while physicians pursue biomedical goals.<sup>22, 33</sup> Both parties may be striving to achieve 'good health' for the patient, but there may be substantial conflict over how health is defined.<sup>34</sup>

Disagreement over specialist referrals also points toward deeper differences in how the goals of care were understood. Patients may have wanted referrals to specialists (especially for pain control and diagnostic imaging) for a variety of reasons. Perhaps they wanted to exhaust all options to relieve the pain.. Doctors resisted making referrals because the confirmation of an arthritis diagnosis by MRI does not change prognosis or treatment. From the physician point of view, it was pointless. Even without changing the treatment, however, confirmation of a diagnosis by MRI might have been needed in the patient's social world in order to achieve valued personal goals (e.g. perhaps a necessary push to join a structured exercise program). In not establishing goals at the outset, disagreement about a plan of care is bound to arise.

Some specific educational recommendations for patients and physicians based on these findings appear in Table 5. Physicians can minimize the impact of arthritis on patient's lives by enabling patients to adapt their lives to the symptoms, especially since symptoms such as pain may never be completely eliminated. Curricula are needed for continuing medical education in the following areas: exercise

prescription, nutritional health, occupational and physical therapy services and alternative medicine. Patients could also benefit from participation in one or all of these areas. It is the belief of the authors that optimal benefit would be realized through a comprehensive program (e.g. self-care course) that includes all or most of these modalities. One example of an educational program includes the use of standardized patients with arthritis as a teaching tool. Standardized arthritis patient have had a positive impact in the education of medical students, 35-37 and their use has expanded to include evaluation of physician skills and needs assessment for physician continuing education. 37

Also, physicians would do well to familiarize themselves with current models of chronic illness. These models describe patient suffering as the end result of a complex chain of events. 20, 21, 29-32, 39-41 Body failures (caused by illness or injury) cause loss of functioning. Loss of functioning causes social isolation and prevents engagement in valued activities. Isolation and inability to do important activities make it increasingly difficult to get social validation for a preferred self-image or identity. Loss of this valued sense of self causes subjective distress. This is the causal chain that patients are constantly trying to disrupt. Physicians often help in this struggle, but sometimes are distracted by their own efforts to cease or slow a pathological process, return physiological parameters to normal ranges, and to achieve biomedical goals that are not patient priorities. These goals are objectively valid, but they may not be consistent with the patient's desire to maintain a preferred image of self. Given a choice between safeguarding a valued identity and achieving a biomedically-defined goal, patients tend to favor the identity goals. 6, 20, 21, 25, 41

The task for physicians who care for patients with arthritis and other chronic illnesses is to negotiate a compromise whereby patients' quality of life goals and high-priority biomedical goals can simultaneously be pursued. It is by virtue of this negotiated compromise that the patients' quality of life, not just the disease, will be improved.

## References

- World Health Organization. The world health report 1997. Geneva: World Health Organization,
   1997.
- 2. Arthritis Foundation. Arthritis fact sheet. Vol. 1999: Arthritis Foundation, 1999.
- Woodwell DA. National Ambulatory Medical Care Survey: 1996 Summary. Advance Data from
   Vital and Health Statistics. Hyattsville, MD: National Center for Health Statistics, 1997.
- Lorig K, Visser A. Arthritis patient education standards: a model for the future. Patient Educ
   Couns 1994; 24:3-7.
- 5. Gerteis M, Edgman-Levitan S, Daley J, Delbanco TL. Through the patient's eyes: Understanding and promoting patient-centered care. San Francisco: Jossey-Bass, 1993.
- Lambert BL, Street RL, Cegala DJ, Smith DH, Kurtz S, Schofield T. Provider-patient communication, patient-centered care, and the mangle of practice. Health Communication 1997; 9:27-43.
- 7. Moore N, Komras H. Patient-focused healing. San Francisco, CA: Jossey Bass, 1993.
- 8. Laine C, Davidoff F. Patient-centered medicine. A professional evolution. JAMA 1996; 275:152-6.
- 9. Hirano PC, Laurent DD, Lorig K. Arthritis patient education studies, 1987-1991: A review of the literature. Patient Educ Couns 1994; 24:9-54.
- Lorig KR, Cox T, Cuevas Y, Kranes RG, Britton MC. Converging and diverging beliefs about arthritis: Caucasian patients, Spanish speaking patients, and physicians. J Rheumatol 1984; 11:76-79.
- 11. Silvers IJ, Hovell MF, Weisman MH, Mueller MR. Assessing physician/patient perceptions in rheumatoid arthritis: A vital component in patient education. Arthritis Rheum 1985; 28:300-307.
- 12. Potts M, Weinberger M, Brandt KD. Views of patients and providers regarding the importance of various aspects of an arthritis treatment program. J Rheumatol 1984; 11:71-75.
- 13. Pfefferbaum B, Levenson PM, van Eys J. Comparison of physician and patient perceptions of communication issues. Southern Medical Journal 1982; 75:1080-1083.

- 14. Laine C, Davidoff F, Lewis CE, et al. Important elements of outpatient care: A comparison of patients' and physicians' opinions. Ann Intern Med 1996; 125:640-645.
- 15. DiMatteo MR, Reiter RC, Gambone JC. Enhancing medication adherence through communication and informed collaborative choice. Health Communication 1994; 6:253-266.
- Roter DL, Hall JA. Doctors talking with patients, patients talking with doctors: Improving communication in medical visits. Westport, CT: Auburn House, 1992.
- 17. Parsons T. Social structure and dynamical processes: The case of modern medical practice. The social system. Glencoe, IL: The Free Press, 1951:429-479.
- Freidson E. Profession of medicine. A study of the sociology of applied knowledge. New York,
   NY: Dodd Mead, 1973.
- Skelton JA, Coyle RT. Mental representation in health and illness. New York: Springer-Verlag,
   1991.
- Charmaz K. Good days, bad days: The self in chronic illness and time. New Brunswick, NJ:
   Rutgers University Press, 1991.
- 21. Charmaz K. Loss of self: A fundamental form of suffering in the chronically ill. Sociol Health Illn 1987; 5:168-195.
- 22. Strauss A, Corbin JM. Shaping a new health care system. San Francisco, CA: Jossey-Bass, 1988.
- Wolf SM. Conflict between doctor and patient. Law, Medicine, and Health Care 1998; 16:197 203.
- 24. Katz J. The silent world of doctor and patient. New York: The Free Press, 1984.
- Chewning B, Sleath B. Medication decision-making and management in a client-centered model.
   Soc Sci Med 1996; 42:389-398.
- Stewart DW, Shamdashani PN. Focus groups: Theory and practice. Newbury Park, CA: Sage,
   1990.
- 27. Morgan DL. Focus groups as qualitative research. Newbury Park, CA: Sage, 1988.
- Lambert BL. The Theme Machine: Theoretical foundation and summary of methods, 46th Annual
   Conference of the International Communication Association, Chicago, IL, 1996.

- 29. Devins GM, Edworthy SM, Guthrie NG, Martin L. Illness intrusiveness in rheumatoid arthritis: Differential impact on depressive symptoms over the adult lifespan. J Rheumatol 1992; 19:709-715.
- Devins GM, Edworthy SM, Seland TP, Klein GM, Paul LC. Differences in illness intrusiveness across rheumatoid arthritis, end-stage renal disease, and multiple sclerosis. J Nerv Ment Dis 1993; 181:377-381.
- 31. Devins GM, Edworthy SM, Paul LC, et al. Restless sleep, illness intrusiveness, and depressive symptoms in three chronic illness conditions: Rheumatoid arthritis, end-stage renal disease, and multiple sclerosis. Journal of Psychosomatic Research 1993; 37:163-170.
- 32. Devins GM. Illness intrusiveness and the psychosocial impact of lifestyle disruptions in chronic life-threatening disease. Adv Ren Replace Ther 1994; 1:251-263.
- Corbin JM, Strauss A. Unending work and care: Managing chronic illness at home. San Francisco, CA: Jossey-Bass, 1988.
- Schultz RM, Holdford DA. Definitions and the meaning of health. In: Smith MC, Wertheimer AI,
   eds. Social and behavioral aspects of pharmaceutical care. Binghampton, NY: Haworth, 1996.
- 35. Branch VK, Lipsky PE. Positive impact of an intervention by arthritis educators on retention of information, confidence, and examination skills of medical students. Arthritis Care Research 1998; 11:32-38.
- 36. Gruppen LD, Branch VK, Laing TJ. The use of trained patient educators with rheumatoid arthritis to teach medical students. Arthritis Care Research 1996; 9:302-308.
- 37. Davis P, Russell AS, Skeith KJ. The use of standardized patients in the performance of a needs assessment and development of a CME intervention in rheumatology for primary care physicians.
  J Rheumatol 1997; 24:1995-1999.
- 38. McClure CL, P. GE, Meredith KE, Gooden MA, Boyer JT. Assessing clinical judgment with standardized patients. J Fam Pract 1985; 20:457-464.
- Conrad P. The meaning of medications: Another look at compliance. In: Conrad P, Kern R, eds.
   The sociology of health and illness: Critical perspectives. New York: St. Martin's, 1994:149-161.

- 40. Corbin J, Strauss AL. Experiencing body failure and a disrupted self image. In: Corbin J, Strauss AL, eds. Unending work and care: Managing chronic illness at home. San Francisco, CA: Jossey-Bass, 1988:49-67.
- 41. Charmaz K. Struggling for a self: Identity levels of the chronically ill. In: Roth J, Conrad P, eds.

  Research in the sociology of health care. Vol. 6: The experience and management of chronic illness. Greenwich, CT: JAI Press, 1987:283-321.

Table 1. Questions and responses in patient focus groups

What is arthritis?	Arthritis was experienced primarily as pervasive and persistent pain. Patients defined arthritis as deterioration, swelling, and inflammation of the bones, joints, and muscles
What causes arthritis and arthritis pain?	Arthritis was believed to be caused by old age, viruses, bacteria, cold, damp, and changing weather, injuries, bursitis, tight-fitting shoes, and air pollution.
How has arthritis affected your life?	Everyday activities such as climbing stairs, making beds, bending, kneeling, sitting for long periods, getting up from chairs, washing floors, and walking in cold weather or on cold floors were identified as pain triggers. Pain made patients cranky, annoyed, and moody, which caused them to withdraw socially.
How satisfied are you with your medical care?	While many praised doctors' willingness to see and listen to them, others believed that doctors could do very little to relieve pain or cure the underlying disease.
How is arthritis affected by exercise?	Patients believed exercise to be an important factor in treatment of arthritis, but most were unsure what exercises to do or how to do them without being injured.
How does arthritis affect activities of daily living?	See "How has arthritis affected your life?"
How does arthritis affect sleep and relaxation?	Patients described difficulty in falling asleep and staying asleep. Interrupted sleep patterns disrupted life for the patients and their families. Relaxation was inhibited by pain, but relaxation was also seen as a way of achieving pain relief by distracting one's attention from the aches and stiffness.
How has arthritis affected your sexuality?	Patients said that arthritis inhibited sexual desire or made sexual activity painful. Disrupted sexual functioning often caused strain in intimate relationships.
How do diet and nutrition affect arthritis?	Diet was seen as an important causal factor in arthritis pain. Red meat, sugar, coffee, and junk food were believed to exacerbate arthritis pain. Vegetables, bran, cereal, fish, and chicken were thought to be good foods for arthritis. Weight loss was seen by some as an important pain reduction strategy. Most used vitamins, nutritional supplements, and other natural product remedies as a means to reduce pain
What resources are available to you in the community for dealing with arthritis?	Patients were aware of various resources in the community, but more information was desired about every topic discussed.

Table 2. Questions and responses in physician focus groups

How much training did you receive about arthritis?	Physicians characterized their training as minimal, superficial, and inadequate.
How comfortable are you performing joint injections?	Most physicians did not perform joint injections due to lack of skills and training, especially in smaller joints. Some physicians were skeptical about the efficacy of joint injections and of pain management specialists in general.
What circumstances cause you to refer a patient to a rheumatologist?	Uncontrolled pain and the need for small joint injections were the most common reasons given for referring patients to rheumatologists.
What about arthritis bothers patients the most?	Physicians stated that patients' main complaints centered around pain, stiffness, and limited mobility.
How comfortable are you providing advice to patients with arthritis about diet and nutrition?	Weight loss through diet and exercise was believed to be very effective, but many physicians were unsure what exercises to recommend.  Recommendations about diet and exercise were complicated by comorbid conditions and needed to be tailored to individual patients.
What role does occupational and/or physical therapy play in treating patients with arthritis?	Occupational therapy and physical therapy were seen as potentially useful, but only when provided by highly skilled therapists with well-defined, short-term, practical treatment goals. Physicians admitted to knowing very little about strategies for functional improvement or exercise.
What kinds of continuing medical education about arthritis would benefit physicians the most?	Continuing education in treatment algorithms, diagnosis, pain management, and the relationship between arthritis and osteoporosis was requested. Physicians believed more emphasis should be placed on joint replacement, group exercise, nutrition and support programs, and on spa-type treatment facilities.
What education would most benefit patients?	Patients were believed to require more education in the incurable, chronic nature of arthritis, along with information about how to overcome disability through diet, exercise, medication and joint replacement.
What frustrates you most about treating patients with arthritis?	Physicians were frustrated by their inability to cure arthritis and relieve chronic pain. They thought too many patients received unnecessary MRI exams that did not alter diagnosis or treatment plans.

# Table 3. Points of agreement between physicians and patients

Pain, immobility, and the accompanying loss of social functioning are the most important problems patients with arthritis face.

Arthritis is incurable.

Doctors are too busy to provide optimal care.

Doctors and patients need more information about diet, exercise, and nutrition.

Activities that reduce social isolation and provide distraction from pain could be as effective as current treatments.

Allowing patients to talk about their pain can be therapeutic.

## Table 4. Areas of disagreement between physicians and patients

Patients perceive value in vitamins and nutritional supplements, but doctors are skeptical.

Doctors see joint replacement as the closest thing to a 'cure', but patients see it as a frightening and impractical option because of the time believed to be needed for recovery.

Some patients want referrals to specialists and high tech diagnostic procedures, but doctors see often see these options as unnecessary.

Doctors see arthritis pain as an "unavoidable part of aging", but patients cannot accept chronic pain so easily.

Doctors think drug therapy can be often be useful in treating arthritis (although they are realistic about effectiveness), but many patients aim to avoid drug therapy wherever possible.

# Table 5. Recommendations for providing patient-centered arthritis care

#### **Recommendation for Patient Education**

Attempt to minimize the impact of arthritis on people's lives, not by treating symptoms, but by enabling patients to adapt their lives to symptoms (e.g., pain) that won't go away.

Create opportunities for social interaction; minimize social isolation.

Create exercise groups.

Provide more information about safe forms of exercise.

Provide information about nutrition.

Employ the knowledge of occupational and physical therapists to promote increased knowledge regarding strategies for functional improvement and physical restoration.

Educate providers and patients about nutritional supplements and herbal therapies.

## **Recommendations for Physician Arthritis Continuing Education**

Create a mechanism that allows doctors to better understand and prescribe occupational therapy, physical therapy, exercise, nutritional consults and alternative medicine interventions with specific, short-term and long-term treatment goals

Create patient education groups focused on all of the areas mentioned above.

Provide additional 'basic training' to physicians in arthritis diagnosis and treatment.

Open a dialogue with patients about the costs and benefits of 'unnecessary' diagnostic procedures (e.g., MRIs).

Take steps to educate patents about benefits of joint replacement surgery.

Allow patients to 'ventilate' about their pain and suffering.

Focus on helping patients live with pain in addition to helping patients eliminate pain.