From aches and pains to timely treatment:

What drives people with arthritis to seek information and treatment?

Arthritis Research Centre of Canada

UBC

The Arthritis Society

Financial support provided by Canadian Institutes of Health Research

Contents

Research Team

Co-Principal Investigators

Linda Li, PT, PhD
Assistant Professor, University of British Columbia
Research Scientist, Arthritis Research Centre of Canada

Catherine Backman, OT, PhD
Associate Professor, University of British Columbia
Research Scientist, Arthritis Research Centre of Canada

Co-Investigators

Paul Adam, MSW
Social Worker, Community Liaison, Mary Pack Arthritis Centre

Anne Townsend, PhD
Post-Doctoral Student, University of British Columbia

Susan Cox, PhD
Assistant Professor, University of British Columbia

Allen Lehman, PhD Candidate
Research Associate, Arthritis Research Centre of Canada

Jolanda Cibere, MD, PhD
Research Scientist, Arthritis Research Centre of Canada

Collaborators and Reviewers

Anamaria Jones, PT, PhD
Visiting Student, Arthritis Research Centre of Canada
University of São Paulo, Brazil

Antonio Avina-Zubieta, MD, PhD (Candidate)
Arthritis Research Centre of Canada

Jamil Natour, PhD
Federal University of São Paulo, Brazil

Imperio Lombardi, PhD
Federal University of São Paulo, Brazil

Griselda Galindo, MD

Hospital de Especialidades Centro Médico Nacional "La Raza," Instituto Mexicano del Seguro Social

Research Staff

Zubin Amarsi, BSc, MHA; *Research Coordinator*
Arthritis Research Centre of Canada

Cynthia MacDonald, BHK; *Research Assistant*
Arthritis Research Centre of Canada

Katie Rogers; *Research Assistant*
Arthritis Research Centre of Canada

List of Acronyms

ACR	American College of Rheumatology
ARC	Arthritis Research Centre of Canada
CAT	Complementary and Alternative Therapies
DMARD	Disease-Modifying Anti-Rheumatic Drug
KT	Knowledge Translation
NSAID	Non-Steroidal Anti-Inflammatory Drugs
MRI	Magnetic Resonance Imaging
OA	Osteoarthritis
OT	Occupational Therapist
PT	Physical Therapist
RA	Rheumatoid Arthritis
TAS	The Arthritis Society
UBC	University of British Columbia

Executive Summary

Arthritis is the most common cause of severe chronic pain and disability in Canada, and currently affects about four million Canadians (aged $\geq$15 years). From the patient's perspective, the most important goals of arthritis treatment are to control pain, limit functional debility and maintain a normal life. There is mounting evidence that patients with arthritis benefit from a combination of pharmacological and non-drug treatments; however, the literature also suggests that many people with arthritis do not receive effective treatments in a timely manner.

Our ultimate goal was to use the available information to develop interventions for improving arthritis care and health service delivery. Specific objectives of this project are to:

1. Understand the decision-making process in seeking help for osteoarthritis (OA) and inflammatory arthritis
2. Identify gaps in the literature pertaining to patients' help-seeking
3. Synthesize information about individual, social and cultural determinants associated with help-seeking among people with arthritis (ongoing)
4. Propose interventions to overcome barriers and facilitate access to appropriate treatment and information (ongoing)

We conducted a scoping review to identify the literature related to help-seeking in arthritis. Eligible articles were mapped onto three areas: (1.) type of arthritis, (2.) type of information/treatment sought by participants, and (3.) study design. Areas where questions can be developed for further quantitative or qualitative systematic reviews were identified.

The initial literature search yielded 31,146 articles; of those, 301 passed the title and abstract screening. After the detailed review, **120** papers remained eligible. The majority of the papers address help-seeking primarily in rheumatoid arthritis (RA; N = 48), OA (N = 30), and general arthritis (N = 28). Only eight papers involved other types of conditions: ankylosing spondylitis (N = 3), lupus (N = 4) and Lyme disease (N = 1). Six papers were categorized as other because the type of arthritis was not clearly specified.

Our analysis identified four broad themes of research on help-seeking in people with arthritis: 1.) seeking diagnosis, 2.) seeking traditional treatments and health professional visits, 3.) seeking complementary and alternative therapies and 4.) Seeking arthritis-related information.

This scoping review has identified seven areas where further research synthesis is possible:

1. Factors affecting the decision to seek help for early arthritis symptoms (a meta-synthesis)
2. The experience of psychosocial distress in people with arthritis (a meta-synthesis)
3. Does inequity exist in health service utilization by people with RA? (a meta-analysis)
4. The decision to use medication for arthritis (a meta-synthesis)
5. Factors associated with the use of medication for arthritis (a quantitative review)
6. Decisions regarding total joint replacement surgery (a meta-synthesis)
7. Decisions to use complementary and alternative therapies (a meta-synthesis)

Chapter 1: *I*ntroduction

Arthritis is the most common cause of severe long-term pain and disability in Canada.[1;2] About four million Canadians currently have arthritis and the number has been projected to be six million by 2026.[2] Patients often need a combination of pharmacological and non-drug treatments over the course of the disease. For example, in people with rheumatoid arthritis (RA), early treatment with disease-modifying anti-rheumatic drugs (DMARDs) can prevent irreversible joint damage. However, despite the evidence of DMARDs' effectiveness, only about half of people with RA reported having used one over a five-year period.[3;4] The situation is similar for osteoarthritis (OA). Although physical activity and weight management are recommended as the first-line treatment for OA,[5-9] only about one in four patients were physically active or received weight-management interventions.[10]

A patient's decision about a treatment is a complex process and is influenced by a multitude of factors. In the current study, we review the literature on factors that influence people's **help-seeking** behaviour. We conceptualize **help-seeking** as the process through which people decide if, when and how they will use health services as a part of the overall illness-management strategy within the context of the health care system and their daily lives. It encompasses the practice of <u>information-seeking</u> from health professionals or other informal sources (e.g., friends, family, Internet) and <u>treatment-seeking</u> from health professionals or other sources (e.g., over-the-counter therapies).[11]

Scope of the Project and Objectives

This report describes a systematic review of the literature on help-seeking in people with arthritis. Our ultimate goal was to use the information to develop interventions for improving arthritis care and health service delivery. CIHR approved the research grant in March 2007 and funding was in place by April 2007. The literature search and review commenced soon after.

The specific objectives of the review were to:

1. Understand the decision-making process in seeking help for OA and inflammatory arthritis such as RA
2. Identify gaps in the literature pertaining to patients' help-seeking
3. Synthesize information about individual, social and cultural determinants associated with help-seeking among people with arthritis
4. Propose interventions to overcome barriers and facilitate access to appropriate treatment and information

The results of Objectives 1 and 2, and the ongoing activities related to Objective 4, are described in this report. Data analysis for Objective 3 is underway and is expected to be completed in September 2009.

Chapter 2: Background

Which treatments are effective for people with arthritis?

From the patient's perspective, the most important goals of arthritis treatment are to control pain,[12-14] limit functional disability and maintain a normal life.[15] There is mounting evidence that patients with arthritis benefit from a combination of pharmacological and non-drug treatments. In OA, the most common form of arthritis (affecting 10% of the population), therapeutic exercises, education programs, physiotherapy, occupational therapy, weight management and non-opioid analgesics are recommended for those with mild symptoms.[16-19] If patients are unresponsive to this treatment regimen, the use of non-steroidal anti-inflammatory drugs (NSAIDs) in addition to non-drug therapy is appropriate. Judicious use of intra-articular steroid injections is also effective in patients with symptomatic effusion.[16;17] For late-stage OA in hips or knees, there is solid evidence supporting the use of total joint replacement surgeries.[16;20-22]

In RA, a form of inflammatory arthritis affecting about 1% of the population, early use of DMARDs can prevent irreversible joint damage, especially if they are used in the first two years.[23;24] Among patients who have failed to respond to DMARDs, biologic therapies have been associated with significant improvement in disease activity.[25;26] Further, education programs are effective in increasing patients' confidence in self-care,[27-29] while exercise and physical modalities (e.g., TENS and laser) can be used for short-term pain control.[30] In other types of inflammatory arthritis, including spondyloarthropathies, current evidence also supports early medical treatment with adjuncts of exercise and education.[31]

Are people with arthritis using appropriate treatment?

Many patients with arthritis did not receive effective and timely treatments. In 2002, the USA's Arthritis Foundation developed 22 indicators to assess the quality of care in OA.[32-34] When the indicators were applied to a community-based OA population in Ontario, only about 60% of patients had appropriately used acetaminophen for pain, 40% had tried exercise and 23% had participated in education programs.[35] Also, fewer than 15% of people with severe arthritis were "definitely willing" to undergo total joint replacement surgeries despite the focus on wait list management.[36] Other research has reported patients using treatments that are ineffective or lack scientific evidence. For example, about 32% of patients had tried massage, 28% homeopathic/herbal remedies, 10% magnets and 7% reflexology,[13] none of which have demonstrated effectiveness in treating arthritis. The situation is similar with RA. Only 43% and 35% of the RA population in British Columbia (BC) report having used a DMARD over a 5-year and 2-year period, respectively.[3] In Ontario, 58% of the RA population had used DMARDs.[4] Further, only about 30% participated in a health-professional-supervised exercise program.[13;37] Overall, the use of treatment by people with arthritis is far from adequate.

What is known about factors relating to help-seeking in people with arthritis?

Individual characteristics (e.g., age, gender, education), social factors and cultural background, as well as knowledge and perception about a treatment and health status can influence information- and treatment-seeking behaviours. Research on OA management has consistently shown that the use of pain medication improves in individuals who are older, are female,[38;39] have a higher perceived health state[40] and understand the drug's purpose.[41] Having a higher number of co-morbid conditions interferes with the use of pain medications, as do concerns about addiction and denial of the disease and pain.[42] Perceptions of pain and disease status also affect an individual's decisions about joint replacement surgeries.[43] The use of mainstream non-drug treatment is generally associated with a higher level of disability and a higher income.[44] As well, people with RA tend to use more non-drug treatment than people with OA.[45] Finally, analyses from our recent survey suggest an association between individuals' perceptions of effectiveness and use of a non-drug treatment, regardless of the available evidence about the treatment.[13]

Another factor is the lack of an integrated system for arthritis care, which we conceptualize as a continuum from the person's awareness of their symptoms and initial access to health professionals to the appropriate diagnosis, treatment, follow-up and self-management. Arthritis management has been haphazard at the primary care level, with wide variations in prescriptions and referrals to specialists and rehabilitation services.[46;47] For example, in BC only 48% and 34% of the RA population saw a rheumatologist at 5 and 2 years after diagnosis, respectively.[3] The use of physiotherapy services was also low (46%),[3] given the known effects of RA on mobility and function. A lack of overall coordination in arthritis care may pose a barrier for patients in recognizing the need to seek appropriate treatments.

Yet another factor relates to challenges in identifying early arthritis. Current diagnostic criteria for OA rely on x-ray findings, but the concordance between joint symptoms and radiographic findings is poor.[48] A recent population-based study using MRI suggested that 55% of people with knee pain had OA that was not evident on x-rays.[49] Uncertainties in the diagnosis of early OA might lead people to think that no treatment is required at that stage. Misinformation, such as considering mild OA as a part of normal ageing, also contributes to delays in seeking treatment.[43]

Finally, an inadequate supply of qualified health professionals can hinder people's decisions about help-seeking. The Canadian Rheumatology Association recommended one rheumatologist per 70,000 Canadians, which translates as 500 rheumatologists.[50] However, there are currently only 329 rheumatologists in Canada, with most practising in urban regions.[51] Orthopaedic surgeons are also in short supply.[52] Further, only about 450 physiotherapists work in rheumatology, and most of those practise in Ontario and BC.[53] People may not be accessing appropriate treatment because of maldistribution or lack of services.

What would this review add to the current provincial chronic care initiatives?

To our knowledge, this research synthesis project was the first to summarize the individual, social and cultural determinants of help-seeking behaviours in arthritis. Current chronic care initiatives, including arthritis care, focus mainly on waiting list management,[54] evidence-based practice in primary and specialty care,[55;56] expanded roles for allied health professionals[57-61] and self-management[62] by targeting health-system and professional-related factors. By including social and behavioural sciences literature, we synthesized determinants beyond the scope of clinical and health service research. This would allow health care administrators, policy makers and researchers to incorporate relevant determinants in the planning of service delivery models and complementary resources (e.g., transportation, information technologies, exercise facilities), leading to the development of a patient-centred strategy for arthritis care. Further, consumer groups would be able to use the knowledge to develop strategies for sharing evidence-based information about arthritis management with other patients and the public.

Chapter 3: Methods

Search Strategy

We conducted a systematic review of the health, behavioural and social sciences literature on determinants of people's help-seeking. We used Medline, CINHAL, EMBASE, ERIC, PsycINFO and SocioFile to search papers published between 1981 and 2007 that addressed patient decision-making of the included treatments. We expect that pre-1981 information about determinants is likely to be out of date. Papers written in languages other than English were included. We also examined reference lists of retrieved articles and periodically searched the databases after the initial search to identify additional articles. The list of search terms was developed in consultation with a senior librarian with extensive experience in Cochrane systematic reviews (M. Doyle-Waters). The search strings for Medline (Appendix 1) were adapted for other databases.

Scoping Review: Article Selection

To identify areas where primary studies on help-seeking in arthritis are available, we conducted a scoping review on the topic. Scoping reviews are considered to be the preliminary process that identifies areas of research where subsequent focused systematic reviews may be performed.[63] In this study, we used the scoping review to highlight the range of research in arthritis help-seeking and to identify gaps for future research.

Eligible articles were original studies that describe or evaluate individual, social and cultural determinants associated with patients' seeking treatment or information for managing OA and inflammatory arthritis. The latter included RA, spondyloarthropathies (e.g., ankylosing spondylitis, psoriatic arthritis), connective tissue diseases (e.g., systemic lupus erythematosus, scleroderma) and juvenile idiopathic arthritis. Articles retrieved from the database search were first uploaded into Refworks, and then to Trialstat SRS4.0 for screening and review.

The article selection involved a two-phase screening. In the first phase, two reviewers screened the title and abstract of each reference to identify studies that met the eligibility criteria. Eight researchers and two research staff were involved in this process. Any disagreements were discussed by the two reviewers. If the reviewers could not resolve their disagreement, the reference was then discussed at the weekly Aches & Pains Review Team meeting.

The second phase involved an in-depth review of the included articles. Because of the diverse backgrounds of the reviewers (six researchers and two research staff), there was considerable conflict in the pilot review. We subsequently had two meetings to discuss the disagreements and modify the criteria to improve clarity. In addition, the team agreed to assign three reviewers for each article.

Articles that passed the screening stage were mapped into three areas: (1.) **Type of arthritis** (OA, RA, spondyloarthropathies, connective tissue disease, general arthritis), (2.) **Type of information or intervention sought by participants** (medication, surgery, allied health interventions, complementary and alternative therapies (CATs), disease-related information) and (3.) **Study design** (qualitative, quantitative). The mapping was initially conducted by one of the Co-Principal Investigators (LL) and was then presented to the Aches & Pains Review Team for further discussion.

Data Extraction and Systematic Review (Ongoing)

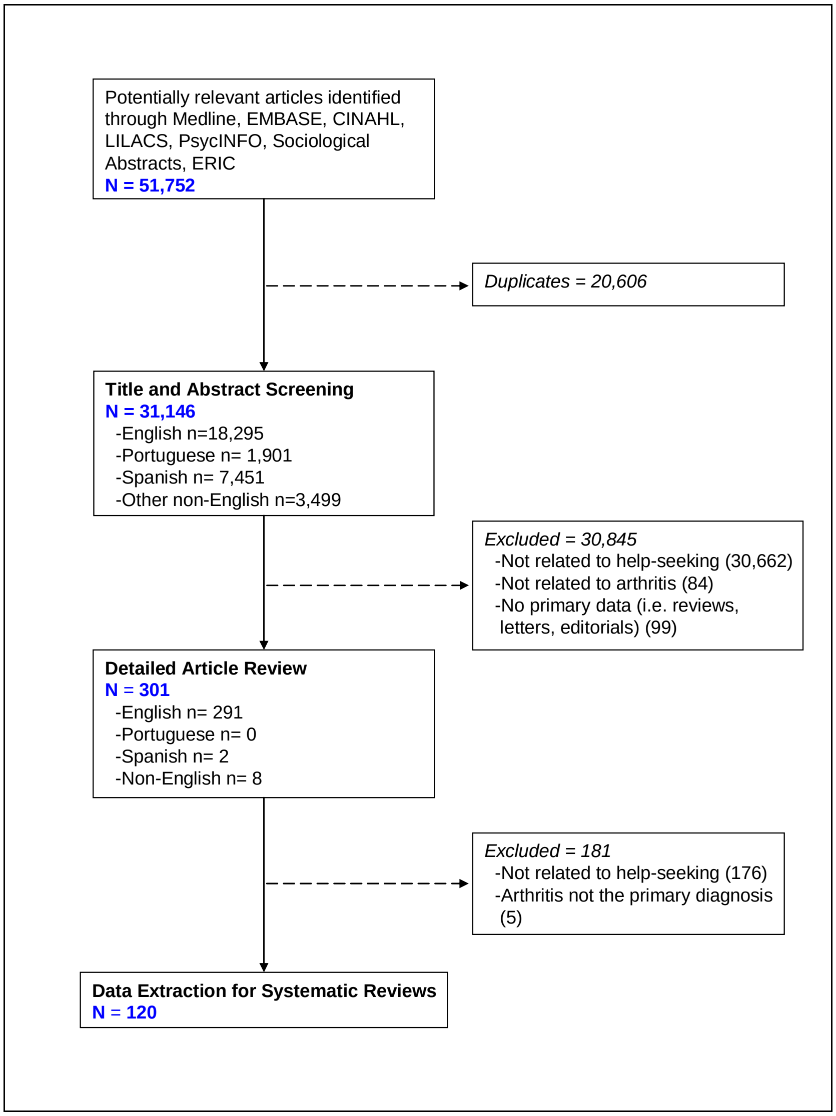
In the next six months, members of the Aches & Pains Review Team will complete specific systematic reviews identified from the mapping exercise. The information collected from quantitative systematic reviews will include: (1) type of arthritis, (2) type of treatment, (3) patient demographic characteristics and disease status and (4) determinants associated with the use (or non-use) of the treatment (Appendix 2: Sample data extraction form). Due to the variation of interventions, participants and outcomes measures for evaluating help-seeking, we will develop a separate form to capture information for each quantitative review. We will test the form with a random sample of five papers. Disagreements in the extracted data will be resolved by discussion and, if consensus is not achieved, a third team member will break the tie. All eligible publications will be subjected to a full review by two team members.

We will also conduct a meta-synthesis on the qualitative studies about people's explanatory frameworks for their illness and the relevance of this for decisions about help-seeking.[64] Sandelowski and Barroso[65] describe meta-syntheses as interpretive and analytic processes by which findings of qualitative studies are aggregated, integrated and summarized. The aim of meta-synthesis is to create larger interpretive artifacts of all studies that examine a target domain (in this case, decision-making about help-seeking), while preserving the integrity and richness of findings in each individual study. Descriptive meta-synthesis involves the synthesis of qualitative findings in a comprehensive analysis of phenomena.[66;67] The review team will inductively develop codes for the analysis.

Chapter 4: Results

The search of electronic databases found 51,752 articles (Figure 1), of which 20,607 were duplicates. From the remaining **31,146** unique articles, 30,845 articles were excluded; of those, 30,662 were not related to help-seeking, 84 were not related to arthritis and 99 were reviews, commentaries or letters. Of the 301 articles that passed for a detailed screening, **120** primary studies were identified as primary studies concerning help-seeking in arthritis.

Figure 1: Literature search strategy



Most of the papers included were published in 2006, and they came mainly from the US and the UK. We mapped the 120 articles by the type of arthritis, the type of treatment/intervention and the study design (Table 1). An annotated bibliography, organized according to the three domains, is presented in Appendix C.

Table 1: Literature mapping[1]

	Rheumatoid arthritis		**Osteoarthritis**		**General arthritis[2]**			**Other[3]**	
	Qual[4]	**Quant[4]**	**Qual**	**Quant**	**Qual**	**Quant**	**Mixed[4]**	**Qual**	**Quant**
Seeking:									
Diagnosis	5	1	2	1	4	3	1	1	--
Medication	11	10	5	6	7	7	--	3	1
Allied health treatments	9	17	3	7	3	10	--	3	1
Surgery	0	3	11	7	3	6	--	--	--
CAT[5]	6	11	1	6	4	11	--	3	1
Arthritis information	6	18	4	4	3	10	--	--	--

[1] Articles can belong to more than one category.
[2] 'General arthritis' includes unspecified arthritis. Ankylosing spondylitis and connective tissue diseases, such as lupus, are also included in this category because of the small number of articles.
[3] 'Other' includes articles with unclear diagnosis, such as 'upper limb pain' and 'thumb pain.'
[4] Qual = Qualitative studies, Quant = Quantitative studies, Mixed = Mixed methods studies.
[5] CAT = Complementary and alternative therapy.

After a detailed review of the articles in each group, we further organized them into four broad themes:

1. **Seeking diagnosis:** This theme focuses on patients' experiences with early joint symptoms and seeking a diagnosis.
2. **Seeking traditional treatments and health professional visits:** This theme focuses on the complexity involved in patients' decisions to use (or not use) a treatment or to consult (or not consult) a health professional. It also addresses the interplay among predisposing, enabling and needs factors associated with health services and treatment use.
3. **Seeking complementary and alternative treatments (CAT)**: This theme addresses the factors associated with the use of CAT and the underlying reasons for the decision.
4. **Seeking information about arthritis**: This theme concentrates on patients' search for information in order to make decisions about treatments, and on the factors associated with information-seeking.

The following sections highlight the issues discussed under the four themes.

Seeking diagnosis

The majority of studies in this theme focus on patients' experiences with, and interpretations of, the early symptoms of RA, OA and other forms of arthritis. In 1982, Bury[68] published the first qualitative study about the illness experience of 30 patients with a new diagnosis of RA. He highlighted the process of people who attempted to explain away the early signs and symptoms, and only sought medical help when they were no longer able to cope. Individuals tended to link the initial symptoms with acute musculoskeletal injuries (e.g., fracture), repetitive strain injuries (e.g., carpal tunnel syndrome) or normal ageing (e.g., ‘wear and tear’). The process tended to be prolonged among those with mild, vague and non-disabling symptoms.[69] Later studies also described how people attempted to accommodate and cloak symptoms at home and at work during the early stage of illness in order to maintain their identity as a healthy person, both to themselves and to others.[68;70;71] This process of ‘normalization of symptoms’[72] sometimes led to a delay in seeking help from medical professionals.

We found two studies that discussed the use of CAT prior to the diagnosis, although neither study directly explored the relationship between CAT use and the delay in help-seeking. A survey in Korea found that almost 95% of people with arthritis used at least one type of CAT before seeing a doctor. The median lag time between the initial symptoms and the first visit was eight weeks, which was longer than the four weeks estimated in an US study conducted around the same period.[73] The survey results were echoed by Candib’s biographical study, which described her decision to seek massage therapy, glucosamine sulphate/chondroitin and over-the-counter pain medications for her neck, back and thumb pain years before she saw a family doctor for a diagnosis.

The literature also highlighted the lengthy and frustrating experience of getting a diagnosis. We identified three sub-themes: 1.) the role of patient-physician communications,;[74] 2.) the patient’s perception of doctors’ knowledge of rheumatologic conditions and early management[75-77] and 3.) psychosocial and financial distresses.[68;71;75;78]

Patient-physician communications: In an analysis of patients’ narratives in a health-related website, Headland described examples of positive medical encounters in which physicians were sympathetic, supportive and resourceful.[74] Individuals who had these experiences appeared to be more likely to use the recommended treatments. However, those who did not feel that the physicians acknowledged their pain and functional limitations subsequently sought a second opinion or changed physicians.

The patient’s perception of doctors’ knowledge about rheumatologic conditions and early management: This topic was addressed by studies in a variety of rheumatologic conditions. Powanda’s biographical study recorded that his knee OA symptoms were overlooked for a period of 20 years by a number of physicians.[75] During that time, he received no recommendation about physical activity, weight management or pain control. Similar reports were also found in studies of early RA [68;76] and systematic lupus erythematosus.[79]

Psychosocial distresses: Research in this area focused on the experience of those with early inflammatory arthritis. Bury described the tremendous anxiety of individuals trying to hide the emerging symptoms from family members and co-workers.[80] Other research illustrated the impact of arthritis-related functional limitations on relationships and family dynamics. For example, two studies described how difficult it was for families of female patients, who used to be the carers, to accept their illnesses.[68;74;79] Younger patients often talked about their fear of the impact of arthritis on their physical appearance and their ability to engage in intimate relationships.[71;81] Finally, for those who had to stop working due to arthritis, financial hardship due to loss of income and increasing medical expense could be a significant source of stress.[78]

Seeking traditional treatments and health professional visits

The majority of primary studies on help-seeking address the individual's use of medications, non-pharmacological interventions (e.g., exercises, psychosocial and counselling), surgical interventions and health professional visits. We have identified two main areas of research: 1.) studies that explored specific factors associated with treatment and health service use and 2.) studies that addressed the complexity involved in patients' decisions to use a treatment or consult a health professional.

Factors associated with the use of treatments and health services: Several surveys used the Andersen's model[82;83] as the framework to explore factors associated with access to health care in RA.[84-87] According to this model, access to health care depends on three types of factors. *Predisposing factors* refer to demographic and social structural characteristics such as age, sex and marital status. *Enabling factors* include resources such as income, health, insurance and costs of health services. *Need factors* represent the most immediate cause for health service use, which may include the patient's perception of the illness, symptoms, diagnosis and disability.

In an earlier US study, Berkanovic et al. reported that need factors were the main driver for physician and physiotherapy visits, and the use of surgery; although predisposing factors and enabling factors were also responsible for the variability in the health service use.[84;85] While need factors accounted for 33% to 50% of the explained variance in physician visits by people with RA, 50% to 67% of the variance was attributable to predisposing and enabling factors.[85] A later population-based survey in Iowa found that the use of physician care for RA was driven largely by need factors, although some variability in the usage pattern was observed between rural and urban regions.[86] Disparities were also found in a recent Dutch study on access to allied health services in those who were older and with lower education, and access to home care in those without health insurance.[87] These findings suggest that although health care utilization by patients with RA was mainly explained by needs, some inequity cannot be ruled out. Overall, the three categories of factors predicted 13% to 20% of the variance of seeking physician and allied health care.[84;85]

We also found studies evaluating specific factors associated with patients' use of arthritis treatments and health services, including: 1.) patients' disease activity and symptoms;[88-90] 2.) socioeconomic factors,[91;92] 3.) ethnic and cultural factors; [93-97] 4.) involvement in their own health care;[98;99] 5.) perceived control of their action, attitude toward the intervention (e.g., perceived effectiveness and adverse events of the treatment), subjective norm and self-efficacy;[100-107] and 6.) good patient-clinician communications.[104;108] Furthermore, patients' priorities should be taken into consideration in developing treatment and future research as their priorities may be different from those of health professionals and researchers.[109]

Complexity in making decisions about the use of treatments and health services: For people with arthritis, making treatment decisions is a complex process of negotiating multiple factors, including balancing the pros and cons. Several studies described patients' ambivalence about taking medication for RA, lupus and OA.[110-114] On the one hand, people followed the recommendation because they believed that the medication would improve their quality of life and help them maintain a good relationship with the clinic staff; on the other hand, they worried about side effects. Patients' social and economic circumstances, their family support and the availability of community network played a role in patients' treatment decisions.[115]

A number of studies also explore the use of joint replacement surgery. While surgery is a cost-effective treatment for severe OA, people sometimes expressed a preference to avoid surgery even if they were a candidate for the procedure. Several qualitative studies reported patients' misconceptions about the severity of pain one should experience before considering surgery,[96;116-118] with some feeling that they did not have sufficient pain for surgery even when their ability to function fully was severely compromised.[116] A recent meta-synthesis has further explored the reasons for patients' decisions about hip and knee surgery based on 10 qualitative studies,[119] from which all the arthritis-related articles have been captured by the current review.

Finally, patients welcome information about treatments.[120] While some may prefer to participate in group education sessions, others prefer to receive the information from health professionals on a one-to-one basis.[121-123]

Seeking complementary and alternative treatments (CAT)

This theme consists of studies that were conducted around the world, including North America,[88;93;104;115;124-141] Europe,[69;108;142-146] Africa,[147] Asia, [148-155] and Australia.[156]

The prevalence of reported CAT use ranged from 38%[142] to 84%;[127] however, the case definitions vary greatly. For example, Chandola asked patients with arthritis who were seen at a rheumatology practice whether they had ever use any CAT, which was not specifically defined.[142] Cronan, however, asked patients with OA to report their use of 19 unprescribed remedies (including dietary supplements, behavioural interventions and exercise, not prescribed by a health professional) within a six-month period.[127] The lack of uniformity in the case definition makes it difficult to estimate the overall use of CAT by people with arthritis.

A number of qualitative studies examined the reasons for people to use CAT. Some reasons were: 1.) perceived ineffectiveness of Western medicine for arthritis,[125] 2.) perceived fewer side effects in CAT compared to Western medicine,[130] 3.) greater selection of interventions,[126] 4.) recommendation of a friend or relative[125;148] and 5.) good working relationship with CAT practitioners.[69;126] A few studies also explored the complex relationship between cultural beliefs and the use of CAT for arthritis management.

Seeking information

Information-seeking is a cross-cutting theme that addresses why and how individuals sought information about their arthritis diagnosis and/or treatments, and the type of information in which they were interested. Studies in this theme described information-seeking as a process that facilitated patients' decisions about seeking care.

Five studies focused specifically on the use of the Internet for health information.[102;157-160] In a large population survey, Millard et al. found that those who were more skeptical about health care, or were dissatisfied or experienced problems with access to health care, reported being more likely to go to the Internet for arthritis-related information.[158] In general, people sought information on the Web without discussing the information with their physicians.[157]

Areas for future systematic reviews

This scoping review has identified seven areas where further research synthesis is possible. The decision is based on the number of articles on the specific topic.

1. Factors affecting the decision to seek help for early arthritis symptoms (a meta-synthesis)
2. The experience of psychosocial distress in people with arthritis (a meta-synthesis)
3. Does inequity exist in health service utilization by patients with RA? (a meta-analysis)
4. Decision to use medication for arthritis (a meta-synthesis)
5. Factors associated with the use of medication for RA, OA and general arthritis (a quantitative review)
6. Decisions regarding total joint replacement surgery (a meta-synthesis)
7. Decisions to use complementary and alternative therapies (a meta-synthesis)

In April 2009, the research team will meet with the patient and health decision maker collaborators to identify other possible topics for reviews.

Chapter 5: Discussion and Knowledge Translation Activities

This study is the first to synthesize the literature on help-seeking in patients with arthritis. One major observation of the scoping review is the large amount of literature that addresses help-seeking and the breadth of research in this field. Most studies focused on decisions on treatments and health services provided by physicians and allied health professionals for RA and OA. In contrast, very little research was found on other rheumatologic conditions. However, since different conditions, such as lupus and ankylosing spondylitis, may pose different challenges in making decisions about treatments, further research is warranted.

It should be noted that studies on factors associated with the use of health services and treatments only predict a small proportion of the variability in people's use of health services. This is not surprising because most of the surveys on health resource use covered only a limited number of factors. Although the Andersen model[82;83] addresses the major factors affecting people's access to health services, it does not address other important variables such as an individual's coping mechanism, self-efficacy or readiness to seek help, and nor does it address the complexity of the help-seeking process. Our ongoing synthesis of studies that address health inequity in the use of RA treatment will provide insight on how to improve research in this area.

We anticipate that the seven review topics will provide a comprehensive view on the current knowledge on help-seeking in arthritis. The results will provide the foundation for further development of interventions to facilitate access to patient-centred arthritis care.

Knowledge Translation Activities

Members of the review team have completed the following research presentations that are related to this review:

1. "Knowledge Translation in Arthritis and Osteoporosis: Developing and Conducting CIHR Knowledge Syntheses." Canadian Physiotherapy Association Congress, Calgary, Canada. May 29, 2009.
2. "Providing care for people with arthritis: Gaps and innovations." Spenshult Hospital Research Institute, Halmstad, Sweden. April 28, 2008.
3. "Health seeking in people with arthritis." Centre for Health Evaluation and Outcome Sciences, St. Paul's Hospital. Vancouver, BC. November 21, 2007.
4. "Health seeking in people with arthritis." Arthritis Research Centre Research Rounds. Vancouver, BC. October 22, 2007.

We continue to update collaborators and the public on the progress of the project by way of our electronic plain language summary* and newsletters†.

Our team is also working with Dr. Ann Cranney's Arthritis and Driving Safety research synthesis team at the Ottawa Health Research Institute to develop three joint workshops in Halifax, Toronto and Vancouver to disseminate the review results. We will invite other CIHR-funded research synthesis teams working on arthritis-related topics to join as partners in these events. Our goal is to streamline the knowledge translation activities that aim at people with arthritis, clinicians, professional associations, and other relevant stakeholders. Finally, input from our collaborators will be sought to develop additional knowledge translation activities.

---

* Plain language summary address: www.arthritisresearch.ca/__page/10155271.4108.0.7083235.2009762.aspx

† Newsletter address: www.physicaltherapy.med.ubc.ca/faculty_staff/faculty_staff_directory/Faculty_Directory/Linda_Li/Aches_Pains_Information.htm

References

(1) Woolf AD, Akesson K. Understanding the burden of musculoskeletal conditions. BMJ 2001; 322(7294):1079-1080.

(2) Arthritis in Canada. An ongoing challenge. H38-4/14-2003E ed. Ottawa, Canada: Health Canada; 2003.

(3) Lacaille D, Anis AH, Guh DP, Esdaile JM. Gaps in care for rheumatoid arthritis: a population study. Arthritis Rheum 2005; 53(2):241-248.

(4) Shipton D, Glazier RH, Guan J, Badley EM, Shipton D, Glazier RH et al. Effects of use of specialty services on disease-modifying antirheumatic drug use in the treatment of rheumatoid arthritis in an insured elderly population. Medical Care 2004; 42(9):907-913.

(5) van Dijk GM, Dekker J, Veenhof C, Van den Ende CH, Carpa Study Group. Course of functional status and pain in osteoarthritis of the hip or knee: a systematic review of the literature. Arthritis Rheum 2006; 55(5):779-785.

(6) Minor M, Stenstrom CH, Klepper SE, Hurley M, Ettinger WH. Work group recommendations: 2002 exercise and physical activity conference, St. Louis, Missouri. Arthritis Rheum 2003; 49(3):453-454.

(7) American Geriatrics Society Panel on Exercise and Osteoarthritis. Exercise prescription for older adults with osteoarthritis pain: Consensus practice recommendations. Journal of American Geriatrics Society 2001; 49:808-823.

(8) Wendelboe AM, Hegmann KT, Biggs JJ, Cox CM, Portmann AJ, Gildea JH et al. Relationships between body mass indices and surgical replacements of knee and hip joints. American Journal of Preventive Medicine 2003; 25(4):290-295.

(9) Christensen R, Bartels EM, Astrup A, Bliddal H. Effect of weight reduction in obese patients diagnosed with knee osteoarthritis: a systematic review and meta-analysis. Ann Rheum Dis 2007; 66(4):433-439.

(10) Li L. British Columbia Osteoarthritis Survey. 2008. Vancouver, Canada, Arthritis Research Centre of Canada.
Ref Type: Report

(11) Rogers A, Hassell K, Nicolaas G. Demanding Patients? Analysing the Use of Primary Care. Buckingham: Open University Press; 1999.

(12) Koehn C, Dooley A, Hofstetter C, Qualman A. Determining the research priorities of people living with arthritis: Listening to patients. The Arthritis Society [2006 Available from: URL:http://www.arthritis.ca/look%20at%20research/cap/patient/default.asp?s=1

(13) Li LC, MacKay C, CARE III Local Planning Committee. CARE III Online Patient Survey - Summary of Preliminary Analysis, www.arthritis.ca/look%20at%20research/surveys/caresummary/default.asp?s=1. 2005.

(14) Heiberg T, Finset A, Uhlig T, Kvien TK. Seven year changes in health status and priorities for improvement of health in patients with rheumatoid arthritis. Ann Rheum Dis 2005; 64(2):191-195.

(15) Bury M. Meanings at risk: the experience of arthritis. In: Anderson R, Bury M, editors. Living with Chronic Illness: The Experience of Patients and Their Families. 1st edition ed. London: Unwin and Hyman; 1988. 89-116.

(16) Recommendations for the medical management of osteoarthritis of the hip and knee: 2000 update. American College of Rheumatology Subcommittee on Osteoarthritis Guidelines. Arthritis Rheum 2000; 43(9):1905-1915.

(17) Pendleton A, Arden N, Dougados M, Doherty M, Bannwarth B, Bijlsma JW et al. EULAR recommendations for the management of knee osteoarthritis: report of a task force of the Standing Committee for International Clinical Studies Including Therapeutic Trials (ESCISIT). Ann Rheum Dis 2000; 59(12):936-944.

(18) Ottawa panel evidence-based clinical practice guidelines for therapeutic exercises and manual therapy in the management of osteoarthritis. Physical Therapy 2005; 85(9):907-971.

(19) Philadelphia Panel evidence-based clinical practice guidelines on selected rehabilitation interventions for knee pain. Physical Therapy 2001; 81(10):1675-1700.

(20) Towheed TE, Hochberg MC, Towheed TE, Hochberg MC. Health-related quality of life after total hip replacement. Semin Arthritis Rheum 1996; 26(1):483-491.

(21) Dieppe P, Basler HD, Chard J, Croft P, Dixon J, Hurley M et al. Knee replacement surgery for osteoarthritis: effectiveness, practice variations, indications and possible determinants of utilization. Rheumatology 1999; 38(1):73-83.

(22) Chang RW, Pellisier JM, Hazen GB, Chang RW, Pellisier JM, Hazen GB. A cost-effectiveness analysis of total hip arthroplasty for osteoarthritis of the hip. JAMA 1996; 275(11):858-865.

(23) Nell VP, Machold KP, Eberl G, Stamm TA, Uffmann M, Smolen JS. Benefit of very early referral and very early therapy with disease-modifying anti-rheumatic drugs in patients with early rheumatoid arthritis. Rheumatology 2004; 43(7):906-914.

(24) Lacaille D. Rheumatology: 8. Advanced therapy. Canadian Medical Association Journal 2000; 163(6):721-728.

(25) van der Kooij SM, de Vries-Bouwstra JK, Goekoop-Ruiterman YP, et al. What Treatment Strategy Should be Chosen after Initial Failure on Methotrexate 25 Mg in

Early Rheumatoid Arthritis? Data from the BeSt Study(Abstract.) 2005 ACR/ARHP Annual Scientific Meeting. Arthritis Rheum 2005.

(26) Goekoop-Ruiterman YP, Vries-Bouwstra JK, Allaart CF, van Zeben D, Kerstens PJ, Hazes JM et al. Clinical and radiographic outcomes of four different treatment strategies in patients with early rheumatoid arthritis (the BeSt study): a randomized, controlled trial.[see comment]. Arthritis Rheum 2005; 52(11):3381-3390.

(27) American College of Rheumatology Subcommittee on Rheumatoid Arthritis Guidelines. Guidelines for the management of rheumatoid arthritis: 2002 Update. Arthritis Rheum 2002; 46(2):328-346.

(28) Ottawa P. Ottawa Panel evidence-based clinical practice guidelines for therapeutic exercises in the management of rheumatoid arthritis in adults. [Review] [144 refs]. Physical Therapy 2004; 84(10):934-972.

(29) Lorig KR, Holman H. Self-management education: history, definition, outcomes, and mechanisms. Annals of Behavioral Medicine 2003; 26(1):1-7.

(30) Ottawa P. Ottawa Panel Evidence-Based Clinical Practice Guidelines for Electrotherapy and Thermotherapy Interventions in the Management of Rheumatoid Arthritis in Adults. Physical Therapy 2004; 84(11):1016-1043.

(31) Zochling J, van der HD, Dougados M, Braun J. Current evidence for the management of ankylosing spondylitis: a systematic literature review for the ASAS/EULAR management recommendations in ankylosing spondylitis. [Review] [199 refs]. Ann Rheum Dis 2006; 65(4):423-432.

(32) Pencharz JN, MacLean CH. Measuring quality in arthritis care: the Arthritis Foundation's Quality Indicator set for osteoarthritis. Arthritis Rheum 2004; 51(4):538-548.

(33) Shekelle PG, MacLean CH, Morton SC, Wenger NS. Assessing Care of Vulnerable Elders: Methods for Developing Quality Indicators.[Miscellaneous Article]. Ann Intern Med 2001; 135(8 (Part 2):Supplement-652.

(34) MacLean CH. Quality indicator for the management of osteoarthritis in vulnerable elders. Ann Intern Med 2001; 135(8):711-721.

(35) Pencharz JN, Li XY, Li LC, Maetzel A, Maguire L, Jansz G et al. Quality of care provided to a community-based sample of patients with osteoarthritis. Arthritis Rheum 2002.

(36) Hawker GA, Wright JG, Coyte PC, Williams JI, Harvey B, Glazier R et al. Determining the need for hip and knee arthroplasty: the role of clinical severity and patients' preferences. Medical Care 2001; 39(3):206-216.

(37) Li LC, Maetzel A, Pencharz JN, Maguire L, Bombardier C, Community Hypertension and Arthritis Project (CHAP) Team. Use of mainstream nonpharmacologic treatment by

patients with arthritis. Arthritis Rheum 2004; 51(2):203-209.

(38) Viller F, Guillemin F, Briancon S, Moum T, Suurmeijer T, van den HW. Compliance with drug therapy in rheumatoid arthritis. A longitudinal European study. Joint, Bone, Spine: Revue du Rhumatisme 2000; 67(3):178-182.

(39) Viller F, Guillemin F, Briancon S, Moum T, Suurmeijer T, van den HW. Compliance to drug treatment of patients with rheumatoid arthritis: a 3 year longitudinal study. J Rheumatol 1999; 26(10):2114-2122.

(40) de KE, van der HD, Landewe R, van der TH, van der LS. The compliance-questionnaire-rheumatology compared with electronic medication event monitoring: a validation study. J Rheumatol 2003; 30(11):2469-2475.

(41) Daltroy LH. Doctor-patient communication in rheumatological disorders. Baillière's Clinical Rheumatology 1993; 7(2):221-239.

(42) Sale JE, Gignac M, Hawker G. How "Bad" Does the Pain Have to Be? A Qualitative Study Examining Adherence to Pain Medication in Older Adults With Osteoarthritis. Arthritis Rheum (Arthritis Care Res) 2006; 55(2):272-278.

(43) Hudak PL, Clark JP, Hawker GA, Coyte PC, Mahomed NN, Kreder HJ et al. "You're Perfect for the Procedure! Why Don't You Want It?" Elderly Arthritis Patients' Unwillingness to Consider Total Joint Arthroplasty Surgery: A Qualitative Study. Med Decis Making 2002; 22(3):272-278.

(44) Li LC, Maetzel A, Pencharz JN, Maguire L, Bombardier C, Community Hypertension and Arthritis Project (CHAP) Team. Use of mainstream nonpharmacologic treatment by patients with arthritis. Arthritis Rheum 2004; 51(2):203-209.

(45) Li LC, Maetzel A, Pencharz JN, Maguire L, Bombardier C, Community Hypertension and Arthritis Project (CHAP) Team. Use of mainstream nonpharmacologic treatment by patients with arthritis. Arthritis Rheum 2004; 51(2):203-209.

(46) Glazier RH, Dalby DM, Badley EM, Hawker GA, Bell MJ, Buchbinder R et al. Management of the early and late presentations of rheumatoid arthritis: a survey of Ontario primary care physicians. CMAJ 1996; 155(6):679-687.

(47) Glazier RH, Dalby DM, Badley EM, Hawker GA, Bell MJ, Buchbinder R et al. Management of common musculoskeletal problems: survey of Ontario primary care physicians. Canadian Medical Association Journal 1998; 158(8):1037-1040.

(48) Peat G, McCarney R, Croft P. Knee pain and osteoarthritis in older adults: a review of community burden and current use of primary health care. Ann Rheum Dis 2001; 60(2):91-97.

(49) Cibere J, Trithart S, Kopec JA, Thorne A, Zhang H, Singer J et al. Pre-radiographic knee osteoarthritis is common in people with knee pain: Results from a population-based

survey. Arthritis Rheum 2005; 52(Suppl):S509.

(50) Submission to Commission on the Future of Health Care in Canada (http://www.hc-sc.gc.ca/english/care/romanow/hcc0148.html). 2001.
Ref Type: Report

(51) Canadian Medical Directory. Canadian Medical Association; 2006.

(52) Badley EM, Rothman L, Stephens MR, Wong M. Availability of Services for People with Arthritis. In: Badley EM, Williams JI, editors. Arthritis & Related Conditions. An ICES Practice Atlas. Toronto, Canada: Institute for Clinical Evaluative Sciences; 1998. 35-62.

(53) Data obtained from seven of 10 physiotherapist regulatory colleges in Canada (British Columbia, Saskatchewan, Manitoba, Ontario, Quebec, New Brunswick, and Newfoundland & Labrador). 2006.
Ref Type: Personal Communication

(54) Noseworthy TW, McGurran JJ. From chaos to order: Making sense of waiting lists in Canada. Final reprot. 2001. Edmonton, Alberta, Western Canada Waiting List Project.
Ref Type: Report

(55) Glazier RH, Badley EM, Lineker SC, Wilkins AL, Bell MJ. Getting a Grip on Arthritis: an educational intervention for the diagnosis and treatment of arthritis in primary care. J Rheumatol 2005; 32(1):137-142.

(56) Ahlmen M. Care led by primary care physicians: the Swedish (rheumatology) model. The Third International Conference on Care in Rheumatic Diseases . 2005. Toronto, Canada, CARE III Conference Planning Committee.
Ref Type: Abstract

(57) Li LC, Davis AM, Lineker S, Coyte PC, Bombardier C. Outcomes of home-based rehabilitation provided by primary therapists for patients with rheumatoid arthritis: Pilot study. PHYSIOTHER CAN 2005; 57:255-264.

(58) Li LC, Davis AM, Lineker S, Coyte PC, Bombardier C. The outcome of patients with rheumatoid arthritis who were referred to received treatment from a primary therapist - A randomized controlled trial. Arthritis Rheum 2006; 55(1):42-52.

(59) Li LC, Maetzel A, Davis AM, Lineker S, Bombardier C, Coyte PC. An economic evaluation of the primary therapist model compared to the traditional therapy model for the management of rheumatoid arthritis.(Accepted on October 18, 2005). Arthritis and Rheumatism (Arthritis Care & Research) 2006.

(60) Campos AA, Graveline C, Ferguson JM, Lundon K, Schneider R, Laxer RM. The physical therapy practitioner: an expanded role for physical therapy in pediatric rheumatology. Physiother Can 2001; 53:282-287.

(61) Campos AA, Graveline C, Ferguson JM, Lundon K, Feldman BM, Schneider R et al. The physical therapy practitioner (PTP) in pediatric rheumatology: high level of patient and parent satisfaction with services. Physiother Can 2002; 54:32-36.

(62) The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century. (Available at: www.doh.gov.uk/healthinequalities). 2000. London, England, Department of Health.
Ref Type: Report

(63) Arksey H, O'Malley L. Scoping studies: towards a methodological framework. Internal Journal of Social Research Methodology 2005; 8(1):19-23.

(64) Williams G. The Genesis of Chronic Illness: Narrative Re-Construction. Sociology of Health and Illness 1984; 6(2):175-200.

(65) Sandelowski M, Barroso J. Writing the Proposal for a Qualitative Research Methodology Project. Qual Health Res 2003; 13(6):781-820.

(66) Paterson BL, Thorne SE, Canam C, Jillings C. Meta-Study of Qualitative Health Research: A Practical Guide to Meta-Analysis and Meta-Synthesis. 2001. Thousand Oaks, California, Sage Publications.
Ref Type: Report

(67) Finfgeld DL. Metasynthesis: The State of the Art--So Far. Qual Health Res 2003; 13(7):893-904.

(68) Bury M. Chronic illness as biographical disruption. Sociology of Health and Illness 1982; 4(2):167-182.

(69) Nyman CS, Lutzen K. Caring needs of patients with rheumatoid arthritis. Nurs Sci Q 1999; 12(2):164-169.

(70) Sakalys JA. Illness behavior in rheumatoid arthritis. Arthritis Care and Research 1997; 10(4):229-237.

(71) van der Ende AG. Patient viewpoint: a reconstruction. Baillieres Clin Rheumatol 1997; 11(1):129-143.

(72) Dingwall R. Aspects of Illness. London: Martin Robertson; 1976.

(73) Chan KWA, Felson DT, Yood RA, Walker AM. The lag time between onset of symptoms and diagnosis of rheumatoid arthritis. Arthritis and Rheumatism 1994; 37(6):814-820.

(74) Headland M. Using a website containing patient narratives to understand people's experiences of living with arthritis. J Orthop Nurs 2006; 10(2):106-112.

(75) Powanda CM. The impatient patient: a personal view of osteoarthritis.

Inflammopharmacology 2003; 11(4-6):317-322.

(76) Skinner N. Rheumatoid arthritis: a patient's perspective. CareManagement 2001; 7(2): Disease Management Digest: Volume 5, Number 2):4-5.

(77) Maddox J. Medical care and the arthritis sufferer: a survey in outer Melbourne. Aust Fam Physician 1981; 10(11):876-882.

(78) Drew D, Hewitt H. A qualitative approach to understanding patients' diagnosis of Lyme disease. Public Health Nurs 2006; 23(1):20-26.

(79) Hale ED, Treharne GJ, Lyons AC, Norton Y, Mole S, Mitton DL et al. "Joining the dots" for patients with systemic lupus erythematosus: personal perspectives of health care from a qualitative study. Ann Rheum Dis 2005; 65(5):585-589.

(80) Bury M. Chronic illness as biographical disruption. Sociology of Health and Illness 1982; 4(2):167-182.

(81) Headland M. Using a website containing patient narratives to understand people's experiences of living with arthritis. J Orthop Nurs 2006; 10(2):106-112.

(82) Andersen RM. Behavioral Model of Families' Use of Health Services. Research Series No. 25. Chicago,IL: Center for Health Administration Studies, University of Chicago Press; 1968.

(83) Andersen RM. Revisiting the behavioral model and access to medical care: Does it matter? Journal of Health and Social Behavior 1995; 36:1-10.

(84) Berkanovic E, Hurwicz ML, Batchlor E. Rheumatoid arthritis and the use of medical services. Arthritis Care Res 1991; 4(1):12-21.

(85) Berkanovic E, Hurwicz ML. Physician visits by rheumatoid arthritis patients: a prospective analysis. Arthritis Care Res 1995; 8(2):73-79.

(86) Saag KG, Doebbeling BN, Rohrer JE, Kolluri S, Mitchell TA, Wallace RB. Arthritis health service utilization among the elderly: The role of urban-rural residence and other utilization factors. Arthritis Care and Research 1998; 11(3):177-185.

(87) Jacobi CE, Triemstra M, Rupp I, Dinant HJ, van den Bos GA. Health care utilization among rheumatoid arthritis patients referred to a rheumatology center: unequal needs, unequal care? Arthritis Rheum 2001; 45(4):324-330.

(88) Cardiel MH, Rojas-Serrano J. Community based study to estimate prevalence, burden of illness and help seeking behavior in rheumatic diseases in Mexico City. A COPCORD study. Clin Exp Rheumatol 2002; 20(5):617-624.

(89) Martin LJ, Griffith SM. High disease activity scores predict the need for additional health services in patients over 60 with rheumatoid arthritis. Musculoskelet care 2006; 4(1):1-

11.

(90) Chung KC, Kotsis SV, Kim HM, Burke FD, Wilgis EF. Reasons why rheumatoid arthritis patients seek surgical treatment for hand deformities. J Hand Surg [Am] 2006; 31(2):289-294.

(91) Riemsma RP, Klein G, Taal E, Rasker JJ, Houtman PM, van Paassen HC et al. The supply of and demand for informal and professional care for patients with rheumatoid arthritis. Scand J Rheumatol 1998; 27(1):7-15.

(92) Hawker GA, Guan J, Croxford R, Coyte PC, Glazier RH, Harvey BJ et al. A prospective population-based study of the predictors of undergoing total joint arthroplasty. Arthritis Rheum 2006; 54(10):3212-3220.

(93) Ibrahim SA, Siminoff LA, Burant CJ, Kwoh CK. Variation in perceptions of treatment and self-care practices in elderly with osteoarthritis: a comparison between African American and white patients. Arthritis Rheum 2001; 45(4):340-345.

(94) Cronan TA, Shaw WS, Gallagher RA, Weisman M. Predicting health care use among older osteoarthritis patients in an HMO. Arthritis Care and Research 1995; 8(2):66-72.

(95) Byrne MM, Souchek J, Richardson M, Suarez-Almazor M. Racial/ethnic differences in preferences for total knee replacement surgery. J Clin Epidemiol 2006; 59(10):1078-1086.

(96) Figaro MK, Williams-Russo P, Allegrante JP. Expectation and outlook: the impact of patient preference on arthritis care among African Americans. J Ambulatory Care Manage 2005; 28(1):41-48.

(97) Suarez-Almazor ME, Souchek J, Kelly PA, O'Malley K, Byrne M, Richardson M et al. Ethnic variation in knee replacement: patient preferences or uninformed disparity? Arch Intern Med 2005; 165(10):1117-1124.

(98) Brekke M, Hjortdahl P, Kvien TK. Involvement and satisfaction: A norwegian study of health care among 1,024 patients with rheumatoid arthritis and 1,509 patients with chronic noninflammatory musculoskeletal pain. Arthritis Care and Research 2001; 45(1):8-15.

(99) Kjeken I, Dagfinrud H, Mowinckel P, Uhlig T, Kvien TK, Finset A. Rheumatology care: Involvement in medical decisions, received information, satisfaction with care, and unmet health care needs in patients with rheumatoid arthritis and ankylosing spondylitis. Arthritis Rheum 2006; 55(3):394-401.

(100) Vetter NJ, Charny M, Lewis PA, Farrow S. Prevalence and treatment of symptoms of rheumatism and arthritis among over 65 year olds: a community profile. Br J Gen Pract 1990; 40(331):69-71.

(101) Chipperfield JG, Greenslade L. Perceived control as a buffer in the use of health care

services. J Gerontol B Psychol Sci Soc Sci 1999; 54(3):146-154.

(102) Liu Y, Doucette WR, Farris KB, Nayakankuppam D. Drug information-seeking intention and behavior after exposure to direct-to-consumer advertisement of prescription drugs. Res Social Adm Pharm 2005; 1(2):251-269.

(103) Liu Y, Doucette WR, Farris KB. Perceived difficulty and self-efficacy in the factor stucture of perceived behavioural control to seek drug information from physicians and phyarmacists. Res Social Adm Pharm 2007; 3(2):145-159.

(104) Hsieh J, Dominick KL. Use of non-pharmacological therapies among patients with osteoarthritis. Aging-Clinical & Experimental Research 2003; 15(5):419-425.

(105) Behairy YM, Motuweh SH, Kathlan KA. A survey of patients' attitude toward total knee replacement in a major center in the Kingdom of Saudi Arabia. Saudi Med J 2004; 25(9):1291-1293.

(106) Swirtun LR, Eriksson K, Renstrom P. Who chooses anterior cruciate ligament reconstruction and why? A 2-year prospective study. Scand J Med Sci Sports 2006; 16(6):441-446.

(107) Gabriel SE, Campion ME, O'Fallon WM. Patient preferences for nonsteroidal antiinflammatory drug related gastrointestinal complications and their prophylaxis. J Rheumatol 1993; 20(2):358-361.

(108) Heijmans M, Foets M, Rijken M, Schreurs K, De Ridder D, Bensing J. Stress in chronic disease: Do the perceptions of patients and thier general practitioners match? Journal of Health Psychology 2001; 6(3):229-242.

(109) Tallon D, Chard J, Dieppe P. Exploring the priorities of patients with osteoarthritis of the knee. Arthritis Care Res 2000; 13(5):312-319.

(110) Goodacre LJ, Goodacre JA. Factors influencing the beliefs of patients with rheumatoid arthritis regarding disease-modifying medication. Rheumatology (Oxford) 2004; 43(5):583-586.

(111) Marshall NJ, Wilson G, Lapworth K, Kay LJ. Patients' perceptions of treatment with anti-TNF therapy for rheumatoid arthritis: a qualitative study. Rheumatology (Oxford) 2004; 43(8):1034-1038.

(112) Bower KN, Frail D, Twohig PL, Putnam W. What influences seniors' choice of medications for osteoarthritis? Qualitative inquiry. Can Fam Physician 2006; 52:342-343.

(113) Garcia Popa-Lisseanu MG, Greisinger A, Richardson M, O'Malley KJ, Janssen NM, Marcus DM et al. Determinants of treatment adherence in ethnically diverse, economically disadvantaged patients with rheumatic disease. J Rheumatol 2005; 32(5):913-919.

(114) Carder PC, Vuckovic N, Green CA. Negotiating medications: Patient perceptions of long-term medication use. J Clin Pharm Ther 2003; 28(5):409-417.

(115) Dyck I. Managing chronic illness: an immigrant woman's acquisition and use of health care knowledge. Am J Occup Ther 1992; 46(8):696-705.

(116) Callaghan JJ. A 76- year-old woman considering total hip replacement. JAMA 1996; 276(6):486-491.

(117) Ballantyne PJ, Gignac MA, Hawker GA. A patient-centered perspective on surgery avoidance for hip or knee arthritis: lessons for the future. Arthritis Rheum 2007; 57(1):27-34.

(118) Hudak PL, Clark JP, Hawker GA, Coyte PC, Mahomed NN, Kreder HJ et al. "You're perfect for the procedure! Why don't you want it?" Elderly arthritis patients' unwillingness to consider total joint arthroplasty surgery: a qualitative study. Med Decis Making 2002; 22(3):272-278.

(119) O'Neill T, Jinks C, Ong BN. Decision-making regarding total knee replacement surgery: A qualitative meta-synthesis. BMC Health Services Research 2007; 7(52).

(120) Ashe B, Taylor M, Dubouloz C. The process of change: listening to transformation in meaning perspectives of adults in arthritis health education groups. Can J Occup Ther 2005; 72(5):280-288.

(121) Barlow JH, Cullen LA, Rowe IF. Educational preferences, psychological well-being and self-efficacy among people with rheumatoid arthritis. Patient Educ Couns 2002; 46(1):11-19.

(122) Mikhail SS, Zwar NA, Vagholkar S, Dennis SM, Day RO. Non-steroidal anti-inflammatory drugs in general practice: a decision-making dilemma. Med J Aust 2007; 187(3):160-163.

(123) Baumann M, Euller-Ziegler L, Guillemin F. Evaluation of the expectations osteoarthritis patients have concerning healthcare, and their implications for practitioners. Clin Exp Rheumatol 2007; 25(3):404-409.

(124) Castillo M, Salcido AL, Orozco C, Osorio CM. Interes del paciente can artritis reumatoide por aprender acerca de la enfermedad. Rev Mex Rheumat 2000; 15(5):131-136.

(125) Rao JK, Arick R, Mihaliak K, Weinberger M. Using focus groups to understand arthritis patients' perceptions about unconventional therapy. Arthritis Care Res 1998; 11(4):253-260.

(126) Rose G. Why do patients with rheumatoid arthritis use complementary therapies? Musculoskelet care 2006; 4(2):101-115.

(127) Cronan TA, Kaplan RM, Kozin F. Factors affecting unprescribed remedy use among people with self-reported arthritis. Arthritis Care and Research 1993; 6(3):149-155.

(128) Ramos-Remus C, Watters CA, Dyke L, Suarez-Almazor ME, Russell AS. Assessment of health locus of control in the use of nonconventional remedies by patients with rheumatic diseases. J Rheumatol 1999; 26(11):2468-2474.

(129) Testerman JK, Morton KR, Mason RA, Ronan AM. Patient Motivations for Using Complementary and Alternative Medicine. Complementary Health Practice Review 2004; 9(2):81-92.

(130) Erickson BE. Radioactive pain relief: Health care strategies and risk assessment among elderly persons with arthritis at radon health mines. J Altern Complement Med 2007; 13(3):375-379.

(131) O'Day B, Dautel P, Scheer J. Barriers to healthcare for people with mobility impairments. Manage Care Q 2002; 10(3):41-51.

(132) Zhang J, Verhoef MJ. Illness management strategies among Chinese immigrants living with arthritis. Soc Sci Med 2002; 55(10):1795-1802.

(133) Ang DC, Ibrahim SA, Burant CJ, Siminoff LA, Kwoh CK. Ethnic differences in the perception of prayer and consideration of joint arthroplasty. Med Care 2002; 40(6):471-476.

(134) Bao Y, Sturm R, Croghan TW. A national study of the effect of chronic pain on the use of health care by depressed persons. Psychiatric Services 2003; 54(5):693-697.

(135) Blake VA, Allegrante JP, Robbins L, Mancuso CA, Peterson MG, Esdaile JM et al. Racial differences in social network experience and perceptions of benefit of arthritis treatments among New York City Medicare beneficiaries with self-reported hip and knee pain. Arthritis Rheum 2002; 47(4):366-371.

(136) Carlson MJ, Krahn G. Use of complementary and alternative medicine practitioners by people with physical disabilities: estimates from a national US survey. Disabil Rehabil 2006; 28(8):505-513.

(137) Lazarus H, Neumann CJ. Assessing undertreatment of pain: the patients' perspectives. J Pharmaceutical Care Pain Symptom Control 2001; 9(4):5-34.

(138) Lewis D, Paterson M, Beckerman S, Sandilands C. Attitudes toward integration of complementary and alternative medicine with hospital-based care. J Altern Complement Med 2001; 7(6):681-688.

(139) Wold RS, Wayne SJ, Waters DL, Baumgartner RN. Behaviors underlying the use of nonvitamin nonmineral dietary supplements in a healthy elderly cohort. Journal of Nutrition, Health and Aging 2007; 11(1):3-7.

(140) Candib LM. Making sense of my thumbs: Coming to terms with chronic illness. Families, Systems and Health 2004; 22(2):139-151.

(141) Feldman DE, Duffy C, De Civita M, Malleson P, Philibert L, Gibbon M et al. Factors Associated With the Use of Complementary and Alternative Medicine in Juvenile Idiopathic Arthritis. Arthritis & Rheumatism: Arthritis Care & Research 2004; 51(4):527-532.

(142) Chandola A, Young Y, McAlister J, Axford JS. Use of complementary therapies by patients attending musculoskeletal clinics. J R Soc Med 1999; 92(1):13-16.

(143) Jacobs JWG, Kraaimaat FW, Bijlsma JW. Why do patients with rheumatoid arthritis use alternative treatments? Clin Rheumatol 2001; 20(3):192-196.

(144) Kay EA, Punchak SS. Patient understanding of the causes and medical treatment of rheumatoid arthritis. Br J Rheumatol 1988; 27(5):396-398.

(145) Ware MA, Adams H, Guy GW. The medicinal use of cannabis in the UK: Results of a nationwide survey. Int J Clin Pract 2005; 59(3):291-295.

(146) Calnan MWDOCWAWC. Illness action rediscovered: a case study of upper limb pain. Sociology of health & illness 2007; 29(3):321-346.

(147) Singh V, Raidoo DM, Harries CS. The prevalence, patterns of usage and people's attitude towards complementary and alternative medicine (CAM) among the Indian community in Chatsworth, South Africa. Journal 2004.

(148) Chan H. The utilization and reasons of choice for Chinese or western medicine among rheumatoid arthritis patients in Hong Kong. Hong Kong Nurs J 2002; 38(3):7-16.

(149) Breuer GS, Orbach H, Elkayam O, Berkun Y, Paran D, Mates M et al. Use of complementary and alternative medicine among patients attending rheumatology clinics in Israel. Israel Medical Association Journal 2006; 8(3):184-187.

(150) Chandrashekara S, Anilkumar T, Jamuna S. Complementary and alternative drug therapy in arthritis. J Assoc Physicians India 2002; 50:225-227.

(151) Cho KJ, Jang SH, Lee SK, Doh WS. Utilization characteristics of health care service for rheumatoid arthritis patients in Korea. Yonsei Med J 1998; 39(3):247-251.

(152) Fadlon J. Unrest in Utopia: Israeli Patients' Dissatisfaction with Non-Conventional Medicine. Soc Sci Med 2004; 58(12):2421-2429.

(153) Kajiyama H, Akama H, Yamanaka H, Shoji A, Matsuda Y, Tanaka E et al. One third of Japanese patients with rheumatoid arthritis use complementary and alternative medicine. Mod Rheumatol 2006; 16(6):355-359.

(154) Kim HA, Seo YI. Use of complementary and alternative medicine by arthritis patients in

a university hospital clinic serving rheumatology patients in Korea. Rheumatol Int 2003; 23(6):277-281.

(155) Lee GBW, Charn TC, Chew ZH, Ng TP. Complementary and alternative medicine use in patients with chronic diseases in primary care is associated with perceived quality of care and cultural beliefs. Fam Pract 2004; 21(6):654-660.

(156) Buchbinder R, Gingold M, Hall S, Cohen M. Non-prescription complementary treatments used by rheumatoid arthritis patients attending a community-based rheumatology practice. Intern Med J 2002; 32(5-6):208-214.

(157) Gordon MM, Capell HA, Madhok R. The use of the Internet as a resource for health information among patients attending a rheumatology clinic. Rheumatology (Oxford) 2002; 41(12):1402-1405.

(158) Millard RW, Fintak PA. Use of the internet by patients with chronic illness. Disease Management and Health Outcomes 2002; 10(3):187-194.

(159) Shuyler KS, Knight KM. What are patients seeking when they turn to the internet? Qualitativecontent analysis of questions asked by visitors to an orthopaedics web site. Journal of Medical Internet Research 2003; 5(4):1-22.

(160) Kim HA, Bae YD, Seo YI. Arthritis information on the Web and its influence on patients and physicians: a Korean study. Clin Exp Rheumatol 2004; 22(1):49-54.

Appendix 1: Search Strategy for Rheumatoid Arthritis / Help-Seeking Using Medline

Database: Ovid MEDLINE(R) 1950 to 2007
Search Strategy:

----

1 arthritis, rheumatoid/ (64091)
2 ((Arthrosis or Arthritis) adj2 (Deformans or Rheumatoid or Rheumatic)).tw. (53853)
3 Polyarthritis Chronica Progressiva.tw. (5)
4 (Rheumatism adj3 Chronic).tw. (512)
5 still's disease, adult-onset/ (544)
6 ((still or still's) adj2 adult onset).tw. (423)
7 or/1-6 (78202)
8 Adaptation, Psychological/ (50196)
9 Faith Healing/ (237)
10 Fear/ (14822)
11 "Health Services Needs and Demand"/ (27132)
12 Morale/ (2258)
13 Motivation/ (33463)
14 Perception/ (13097)
15 Quality of Life/ (62186)
16 Social Perception/ (10426)
17 Social Support/ (29952)
18 Thinking/ (7234)
19 Time Factors/ (761029)
20 decision making/ (43921)
21 choice behavior/ (11224)
22 problem solving/ (15677)
23 judgment/ (7152)
24 uncertainty/ (1964)
25 attitude/ (32195)
26 health knowledge, attitudes, practice/ (35633)
27 attitude to health/ (52811)
28 qualitative research/ (4644)
29 Helping Behavior/ (1646)
30 self efficacy/ (4673)
31 Health Behavior/ (16439)
32 Assertiveness/ (1307)
33 treatment refusal/ (8471)
34 ((information or help) adj5 seek$).tw. (4755)
35 (choice$ or choos$ or option$ or decision$ or preference$ or belief$).mp. (439907)
36 (self adj3 care).mp. (18210)
37 view$.tw. (210573)
38 experience$.tw. (421344)
39 perspective$.tw. (90263)
40 perception$.tw. (78656)
41 satisfaction.tw. (39233)
42 perceived.tw. (53862)
43 concern$.tw. (233841)
44 attitude$.tw. (57828)

45 hope$.tw. (33364)
46 hoping.tw. (529)
47 cope.tw. (10713)
48 coping.tw. (19459)
49 "self-help group$".tw. (992)
50 "support group$".tw. (2722)
51 misperception$.tw. (775)
52 ((search$ or find$ or look$) adj3 (service$ or information)).tw. (4546)
53 (belief$ or prayer$ or custom$).tw. (45690)
54 counsel$.tw. (39896)
55 qualitative.mp. (62777)
56 help.mp. (155286)
57 expectation$.tw. (29364)
58 ((therap$ or rehabilitation or educat$) adj3 (support$ or request or seek$ or want$ or understand$)).mp. (12725)
59 self-reported.tw. (21630)
60 Decision Making.tw. (31034)
61 (feed back or feedback).tw. (46418)
62 focus group$.tw. (7755)
63 interview$.tw. (120462)
64 health surveys/ or health care surveys/ or interviews/ or focus groups/ (61620)
65 Questionnaires/ (163017)
66 Ethnograph$.tw. (2794)
67 phenomenolog$.tw. (7566)
68 survey$.tw. (221209)
69 Communication/ (43924)
70 Disease Management/ (5434)
71 self concept/ (31603)
72 questionnaire$.tw. (153432)
73 help.mp. (155286)
74 participation.tw. (54240)
75 (self adj5 (help or education)).tw. (5649)
76 (self adj5 managment).tw. (1)
77 or/8-76 (2855195)
78 patients/ or inpatients/ or outpatients/ or patient dropouts/ (26528)
79 (patient$ or consumer$ or client$ or resident$).mp. (3256789)
80 or/78-79 (3258971)
81 77 and 80 (997206)
82 Patient Participation/ (11741)
83 patient satisfaction/ (33263)
84 Patient Compliance/ (32359)
85 "patient acceptance of health care"/ (18396)
86 or/82-85 (91821)
87 81 or 86 (1025717)
88 prevention & control.fs. (700170)
89 diet therapy.fs. (28352)
90 drug therapy.fs. (1203713)
91 psychology.fs. (478161)
92 rehabilitation.fs. (115511)
93 surgery.fs. (1169905)

94 therapy.fs. (1034682)
95 therap$.mp. (1429902)
96 treatment$.mp. (2089172)
97 rehabilitat$.mp. (79339)
98 Primary Prevention/ (9337)
99 prevention.mp. (224733)
100 Prescriptions, Drug/ (16640)
101 Drugs, Non-Prescription/ (3641)
102 Drugs, Chinese Herbal/ (14599)
103 therapeutics/ or exp balneology/ or bed rest/ or exp behavior control/ or exp clinical protocols/ or exp complementary therapies/ or exp cryotherapy/ or exp drug therapy/ or exp electric stimulation therapy/ or exp exercise movement techniques/ or hydrotherapy/ or exp musculoskeletal manipulations/ or exp orthopedic procedures/ or exp patient care/ or exp patient isolation/ or exp phototherapy/ or exp physical therapy modalities/ or placebos/ or prescriptions, non-drug/ or exp rehabilitation/ or "activities of daily living"/ or art therapy/ or bibliotherapy/ or dance therapy/ or early ambulation/ or exp exercise therapy/ or music therapy/ or occupational therapy/ or exp "rehabilitation of hearing impaired"/ or rehabilitation, vocational/ or rejuvenation/ or remission induction/ or salvage therapy/ or self care/ or self medication/ or therapies, investigational/ (1267575)
104 self administration/ (6380)
105 patient education/ (49221)
106 health education/ (42305)
107 self help groups/ (6008)
108 self help devices/ (2445)
109 (leaflet$ or booklet$ or pamphlet$).tw. (12021)
110 health promotion/ (30652)
111 Internet/ (24280)
112 or/88-111 (5734795)
113 exp health services/ (1102315)
114 Health Services Accessibility/ (28956)
115 primary health care/ (34676)
116 health resources/ (5990)
117 Health Personnel/ (12628)
118 Health Maintenance Organizations/ (14009)
119 Office Visits/ (3772)
120 Chiropractic/ (2698)
121 Holistic Health/ (5294)
122 Information Services/ (13794)
123 Physician-Patient Relations/ (45125)
124 ((medical or health or information) adj3 (service$ or resources$)).mp. (296952)
125 or/113-124 (1262196)
126 7 and 87 (9327)
127 7 and 87 and 112 (7301)
128 7 and 87 and 125 (1426)
129 or/127-128 (7387)
130 adult/ or aged/ or "aged, 80 and over"/ or frail elderly/ or middle aged/ (4071283)
131 (middle adj3 (age$ or year$)).mp. (2390731)
132 (adult$ or aged or aging or older or elder$ or geriatric).mp. (4508387)
133 or/130-132 (4509833)
134 129 and 133 (5033)
135 limit 134 to yr="1981 - 2007" (4689)

136 limit 135 to english language (3974)
137 135 not 136 (715)

Notes:
General arthritis = yellow
Help seeking = grey
Therapy = green
Health services = turquoise

Therapy search:
127 7 and 87 and 112 (7301)

Health Services search:
128 7 and 87 and 125 (1426)

Combined results:
129 or/127-128 (7387)
136 limit 135 to english language (3974)
137 135 not 136 (715)

Appendix 2: Data Extraction Form

Draft Data Extraction Form

Reviewer initials: _____ **Date:** _____

Title: _____

Webpage: _____

Lead author: _____ **Journal**: _____

Year_____ **Vol.** _____ **Starting page:** _____ **End page:** _____ **Country:** _____

Study Design (check one):

Cross-sectional survey ☐ Observational study ☐ Chart review ☐

Qualitative Study ☐ Other ☐
Specify: __________

Eligibility criteria for review

1. This paper describes / evaluates the process of information seeking and / or treatment seeking	**Yes** ☐	**No** ☐
2. Participants in this study have arthritis	**Yes** ☐	**No** ☐
3. This study involves primary data collection	**Yes** ☐	**No** ☐
4. This study involves secondary data analysis	**Yes** ☐	**No** ☐
5. This paper is an opinion paper / editorial	**Yes** ☐	**No** ☐

Include paper if answer Yes to 1, 2 plus 3 and/or 4

Exclude if answer Yes to 5

SECTION A: General Description

1. Osteoarthritis:

☐ Yes ☐ No

If ‘Yes’, what was the stage of the disease:

☐ Pre-diagnosis ☐ Kellgren-Lawrence Scale 2 ☐ Kellgren-Lawrence Scale 3
☐ Kellgren-Lawrence Scale 4

2. **Inflammatory arthritis:**

☐ Yes ☐ No

If 'Yes', what type?

☐ Rheumatoid arthritis
☐ Psoriatic arthritis
☐ Ankylosing spondylitis
☐ Gout
☐ Lupus
☐ Scleroderma
☐ Other *(please specify)*: ________________________________

What was the stage of the disease:

☐ Pre-diagnosis ☐ Early disease (0-12 months) ☐ Chronic stage (after 12 months)

3. **Type of treatments:** *(Options will be presented in drop-boxes)*

Pharmacological treatments:

☐ Non-opioid analgesics
☐ Biologics
☐ NSAIDs
☐ Oral corticosteroid
☐ DMARDs
☐ Intra-articular steroid injection

Mainstream non-drug treatments:

☐ Exercise
☐ Occupational therapy
☐ TENS
☐ Weight management
☐ Total hip / knee replacement surgeries
☐ Disease specific education
☐ Thermotherapy
☐ Low-level LASER
☐ Hand splints
☐ Physiotherapy
☐ Ultrasound
☐ Mobility aids
☐ Foot orthoses

Complementary & alternative therapies:

☐ Glucosamine sulphate
☐ Yoga
☐ Magnets
☐ Reflexology
☐ Homeopathic remedies
☐ Massage
☐ Meditation
☐ Chinese medicine
☐ Chiropractic treatment
☐ Hypnotherapy

PARTICIPANTS

Inclusion Criteria: ____

Exclusion Criteria: ____

Characteristics:

	Group 1 ______	Group 2 ______	Group 3 ______
Number	______	______	______
Age (Year; SD)	______	______	______
Males / Females	______	______	______
Disease duration (Year; SD)	______	______	______

DETERMINANTS

Treatment 1: ____________________

Determinants:

1. ________________
2. ________________
3. ________________
4. ________________

Treatment 2: ____________________

Determinants:

1. ________________
2. ________________
3. ________________
4. ________________

Treatment 3 ____________________

Determinants:

1. ________________
2. ________________
3. ________________
4. ________________

Treatment 4 ____________________

Determinants:

1. _______________
2. _______________
3. _______________
4. _______________

Appendix 3: Annotated Bibliography

Rheumatoid arthritis: Diagnosis – qualitative studies (N=5)

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness, 4,* 167-182.
Refid: 110721
Main message:

- Chronically ill people can make adaptations to their lifestyle, but may have moments when they feel helpless, such as when symptoms are severe or following surgery.

Summary: The study used semi-structured qualitative interviews with patients with RA to describe the experience of onset and development of RA. The results highlighted the resources (cognitive and material) available to individuals, modes of explanation for pain and suffering, and factors that help explain variation in experience.

Nyman, C. S. & Lutzen, K. (1999). Caring needs of patients with rheumatoid arthritis. *Nursing science quarterly, 12,* 164-169.
Refid: 125910
Main message:

- Interviews with people with RA revealed four predominant themes: seeking help, searching for meaning, uncertainty and fear of being disappointed. These four issues captured the complexities of the physical, emotional, social and existential experiences of the patients.

Summary: Qualitative interviews were conducted in order to identify the caring needs specific to the human experience of having RA and undergoing acupuncture treatment. With the application of Watson's 10 Carative Factors, four themes related to the caring needs of patients with RA who sought acupuncture were identified. These patients have a strong tendency toward and need for seeking help. They are searching for meaning within the context of a chronic disease, and they are coping with the uncertainty and fear of being disappointed because of the chronic aspects of the disease. These needs affect and are affected by the physical, emotional, social and existential events of their lives. Awareness of them by the nurse-acupuncturist will allow him or her to be more aware of the caring needs of these patients.

Sakalys, J. A. (1997). Illness behavior in rheumatoid arthritis. *Arthritis Care and Research, 10,* 229-237.
Refid: 126924
Main message:

- An interview study of women with RA showed that the illness is prolonged, diagnosis and treatment are confusing and dealing with RA causes personal and social stress.

Summary: In this descriptive study, interview and medical records data from 50 female patients were analyzed using quantitative and qualitative techniques. The findings revealed a high incidence of symptom normalization, self-treatment, symptom comparison and delays in diagnosis with multiple misdiagnoses and several physicians being consulted. Most participants reported a lack of validation from their health care providers about the initial symptoms, emotional distress and relief upon receiving an accurate diagnosis. Significant associations were found; for example, (1.) illness-related symptom attributions were associated with fewer physicians consulted and with less invalidation; (2.) life stress events were associated with fewer physicians consulted and with a faster diagnosis; and (3.) remissions were associated with time to diagnosis, the number of physicians consulted and the number of misdiagnoses.

Skinner, N. (2001). Rheumatoid arthritis: a patient's perspective. *CareManagement, 7,* 4-5.
Refid: 127427
Main message:

- Case managers and physicians should work with patients to manage RA for better and more comprehensive care of the patient.

Summary: This study was a biographical narrative of one woman's experience with RA. The central theme of the paper was that "case managers" had a responsibility to work in partnership with physicians to promote patient education and determine appropriate treatment options. This would enable patients to have a high level of functioning and an enhanced quality of life.

Van der Ende, A. G. (1997). Patient viewpoint: a reconstruction. *Baillieres Clinical Rheumatology, 11,* 129-143.
Refid: 128318
Main message:

- From the patient's perspective, more research is needed to improve care for people with RA.

Summary: In this qualitative biographical paper, a 54 year-old man who was diagnosed with RA six years ago reflected on the importance of timely diagnosis, his experience and contact with other people with RA, psychosocial issues and the need for consumer-friendly health care. The author concluded that more research was required to develop ways to improve health care delivery for people with RA.

Rheumatoid arthritis: Diagnosis – quantitative (N=1)

Cho, K. J., Jang, S. H., Lee, S. K., & Doh, W. S. (1998). Utilization characteristics of health care service for rheumatoid arthritis patients in Korea. *Yonsei medical journal, 39,* 247-251.
Refid: 121456
Main messages:

- Patients with RA in Korea take longer to consult a medical doctor compared to patients with RA in the United States.
- One factor that contributes to this lag time includes the use of unconventional medicine (Chinese herbal medicine) or non-prescribed medicine after symptom onset.

Summary: The purpose of this study was to determine the factors responsible for delaying diagnosis and optimal management of RA in Korea. From the study sample of 98 patients, 51 patients consulted an orthopaedic surgeon, 19 patients consulted a Chinese herbal doctor and 16 patients consulted a pharmacist. In this study 59% of patients were diagnosed with RA by an orthopaedic surgeon, and 25% by a rheumatologist. Patients with RA in Korea lost twice as much time when consulting a medical doctor compared to patients with RA in the United States.

Rheumatoid arthritis: Medication – qualitative studies (N=11)

Anonymous. On living with rheumatoid arthritis (1991). *Medical Journal of Australia, 155,* 268-269.
Refid: 120064
Main messages:

- Living with arthritis is difficult both physically and mentally.
- Different treatments produce different side effects. Emotional support is very important to help patients cope with both the disease and the side effects of treatments.

Summary: This article is a narrative by a patient who has lived with rheumatoid arthritis (RA) for over 20 years. The patient described the different treatment options she has tried both successfully and unsuccessfully to manage her arthritis. There is a discussion about the physical treatment options as well as the emotional and psychological treatment options to help with self-esteem and motivation issues. The need for emotional support is intense, but the patient often finds it difficult to seek out support because he or she is feeling low when the disease is at its most debilitating.

Ashe, B., Taylor, M., & Dubouloz, C. (2005). The process of change: listening to transformation in meaning perspectives of adults in arthritis health education groups. *Canadian Journal of Occupational Therapy, 72,* 280-288.
Refid: 110204
Main message:

- Education groups may facilitate the adoption of healthy behaviours in people with arthritis.

Summary: This study used qualitative interviews to explore patients' experiences in two different arthritis education groups to develop an understanding of meaningful group experiences. Ten participants with RA or other inflammatory arthritis were recruited. Individual and focus group interviews provided descriptions of experiences. The results showed that arthritis education group experiences led to improved perceptions of an ability to cope with the chronic disease. The idea that the patient's process of change can lead to healthy behaviours and desired health outcomes was also discussed.

Barlow, J. H., Cullen, L. A., & Rowe, I. F. (2002). Educational preferences, psychological well-being and self-efficacy among people with rheumatoid arthritis. *Patient Education & Counseling, 46,* 11-19.
Refid: 110302
Main messages:

- Education on the disease, treatments and emotional issues should be conducted on a one-to-one basis.
- Some patients with RA prefer group interventions for learning about self-management and exercise.

Summary: This mixed method design examined patients' preferences for interventions, as well as psychological well-being and self-efficacy. The results revealed that patients preferred education about the disease and its treatment, as well as emotional issues, to be delivered on a one-to-one basis by health professionals. Group interventions were the preferred format for self-management, exercise and relationship issues, whereas videos were thought to be useful for demonstrating the use of aids and showing how other families cope. The status of both physical and psychological health were correlated with arthritis self-efficacy.

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness, 4,* 167-182.
Refid: 110721
Main message:

- Chronically ill people can make adaptations to their lifestyle, but may have moments when they feel helpless, such as when symptoms are severe or following surgery.

Summary: The study used semi-structured qualitative interviews with patients with RA to describe the experience of onset and development of RA. The results highlighted the resources (cognitive and material) available to individuals, modes of explanation for pain and suffering, and factors that help explain variation in experience.

Carder, P. C., Vuckovic, N., & Green, C. A. (2003). Negotiating medications: Patient perceptions of long-term medication use. *Journal of clinical pharmacy and therapeutics, 28,* 409-417.
Refid: 121282
Main message:

- During the process of managing chronic illness, patients may resist taking medications due to concerns about becoming dependent on them.

Summary: The purpose of this qualitative study was to investigate how adults with chronic illnesses perceived their need to take medications during the course of their illness. The results demonstrated that participants struggled over changing their self-identify from that of a well person to someone who needed medical intervention. There was also a struggle over negotiations with health care providers about the use of medications. The authors concluded that patients experienced not only physical but also emotional side effects from medications.

Chan, H. (2002). The utilization and reasons of choice for Chinese or western medicine among rheumatoid arthritis patients in Hong Kong. *Hong Kong Nursing Journal, 38,* 7-16.
Refid: 121384
Main message:

- In Hong Kong, patients' beliefs in Chinese and Western medicine, the cost of treatments and the effects of treatments are associated with treatment preferences and use.
- Chinese medicine is often used because a friend or relative recommends it and Western medicine is often used because a physician recommends it.

Summary: This mixed method study examined the utilization pattern and reasons for patients with RA using Chinese and/or Western medicine. Most patients used Chinese medicine because it was recommended by a friend or relative, and most of those who used Western medicine were acting on the recommendations of physicians.

Dyck, I. (1992). Managing chronic illness: an immigrant woman's acquisition and use of health care knowledge. *American Journal of Occupational Therapy, 46,* 696-705.
Refid: 122122
Main message:

- For occupational therapy, careful consideration needs to be made about the social and economic circumstances of the client's life, especially for those who are disadvantaged.

<u>Summary:</u> This case study illustrated the role of family, community networks and workplace in the management of RA from the perspective of a Chinese-Canadian immigrant woman. Occupational therapy in a clinical setting was indentified as an important component in the management of her conditions. It showed how health care decisions were related to her life as a working-class immigrant woman.

Garcia Popa-Lisseanu, M. G., Greisinger, A., Richardson, M., O'Malley, K. J., Janssen, N. M., Marcus, D. M., Tagore, J., & Suarez-Almazor, M. E. (2005). Determinants of treatment adherence in ethnically diverse, economically disadvantaged patients with rheumatic disease. *Journal of Rheumatology, 32*, 913-919.
Refid: 122724
<u>Main message:</u>

- The main barriers to adherence to treatment are fear of side effects, financial problems, difficulty in navigating the public health system, and perceived treatment inefficacy.

<u>Summary:</u> This study aimed to examine the factors that affect adherence to medical recommendations among ethnically diverse and economically disadvantaged patients with RA and systemic lupus erythematosus (SLE) in Houston, Texas. The majority of participants reported experiencing difficulty in adhering to their treatment. Patients with SLE or RA reported similar barriers to adhering to treatment and to keeping appointments. The authors concluded that patients' perceptions of, and experiences with, the health system influenced their adherence to treatment.

Goodacre, L. J. & Goodacre, J. A. (2004). Factors influencing the beliefs of patients with rheumatoid arthritis regarding disease-modifying medication. *Rheumatology, 43,* 583-586.
Refid: 122967
<u>Main message:</u>

- The complex belief systems of patients with RA about disease-modifying anti-rheumatic drugs (DMARDs) are informed by a wide variety of sources, including health care professionals, newspapers, magazines, self-help group newsletters, the Internet and television. Patients’ views continue to evolve as they learn more about this type of medication.

<u>Summary:</u> This study used semi-structured interviews, activity diaries and focus groups to examine the views about DMARDs among people with RA. Results showed that DMARDs were perceived as central to the management of RA, but there were strong concerns about potential long-term effects. Patients’ judgements of efficacy were influenced by the degree of symptom relief, occurrence of side effects and perception of alternative treatment options. Perception, reporting and tolerance of side effects differed widely among individuals. The authors concluded that understanding individuals’ belief systems could facilitate the provision of appropriate information and support for making decisions about treatment use.

Marshall, N. J., Wilson, G., Lapworth, K., & Kay, L. J. (2004). Patients' perceptions of treatment with anti-TNF therapy for rheumatoid arthritis: a qualitative study. *Rheumatology,* 43, 1034-1038.
Refid: 125232
<u>Main message</u>:

- In general, patients' experience of anti-TNF therapy was positive, particularly in terms of physical function and well-being, but some patients felt that it did not live up to their expectations.

Summary: In this study, separate focus groups were conducted for patients treated with infliximab and etanercept in an effort to explore patients' experience of and views about the treatments. Five main themes were identified: patients' expectations of the effectiveness of treatments, their actual experience of the treatment and its effects, their concerns about taking a new class of drug, their views about the BSR Biologics Registry process and costs. The results indicated that patients' experience of anti-TNF therapy was good, particularly in terms of physical function and well-being, although it did not live up to the very high expectations of some patients. While the BSR BR process caused initial apprehension, patients had personal and altruistic reasons for being happy to comply with monitoring requirements.

Van der Ende, A. G. (1997). Patient viewpoint: a reconstruction. *Baillieres Clinical Rheumatology, 11,* 129-143.
Refid: 128318
Main message:

- From the patient's perspective, more research is needed to improve care for people with RA.

Summary: In this qualitative biographical paper, a 54 year-old man who was diagnosed with RA six years ago reflected on the importance of timely diagnosis, his experience and contact with other people with RA, psychosocial issues and the need for consumer-friendly health care. The author concluded that more research was required to develop ways to improve health care delivery for people with RA.

Rheumatoid arthritis: Medication – quantitative studies (N=10)

Bridges, M. J., Coady, D., Kelly, C. A., Hamilton, J., & Heycock, C. (2003). Factors influencing uptake of influenza vaccination in patients with rheumatoid arthritis. *Annals of the Rheumatic Diseases, 62,* 685.
Refid: 121027
Main messages:

- The use of influenza vaccine in patients with RA taking MTX is suboptimal.
- The reasons for this include patient concerns over side effects and beliefs about vaccine inefficacy, and the fact that the patients are not being offered the vaccine.

Summary: This quantitative study looked at the factors that influenced the uptake of the influenza vaccine in RA patients. Awareness of vaccination by patients who had received it came most commonly from family doctors or nurses. Advice about immunization mainly came from primary care, with little contribution from secondary care. The most common reasons for non-uptake of vaccination were patients not being offered the vaccine and not realizing they needed it, concerns about side effects and beliefs about vaccine inefficacy.

Cardiel, M. H. & Rojas-Serrano, J. (2002). Community-based study to estimate prevalence, burden of illness and help seeking behavior in rheumatic diseases in Mexico City. A COPCORD study. *Clinical & Experimental Rheumatology, 20,* 617-624.

Refid: 110792

Main message:

- A general practitioner treated 72% of patients with rheumatic diseases in Mexico City. Most patients responded well to the prescribed medication.

Summary: The purpose of this study was to estimate the prevalence of rheumatic diseases in a suburban community in Mexico City. The burden of illness and help-seeking behaviour of patients with rheumatic diseases were also examined. The results indicated that 419 participants (17%) had reported pain in the last seven days due to musculoskeletal disorders and 13% of the total sample had experienced some form of treatment.

Cho, K. J., Jang, S. H., Lee, S. K., & Doh, W. S. (1998). Utilization characteristics of health care service for rheumatoid arthritis patients in Korea. *Yonsei medical journal, 39,* 247-251.

Refid: 121456

Main messages:

- Patients with RA in Korea take longer to consult a medical doctor compared to patients with RA in the United States.
- One factor that contributes to this lag time includes the use of unconventional medicine (Chinese herbal medicine) or non-prescribed medicine after symptom onset.

Summary: The purpose of this study was to determine the factors responsible for delaying diagnosis and optimal management of RA in Korea. From the study sample of 98 patients, 51 patients consulted an orthopaedic surgeon, 19 patients consulted a Chinese herbal doctor and 16 patients consulted a pharmacist. In this study 59% of patients were diagnosed with RA by an orthopaedic surgeon, and 25% by a rheumatologist. Patients with RA in Korea lost twice as much time when consulting a medical doctor compared to patients with RA in the United States.

Gabriel, S. E., Campion, M. E., & O'Fallon, W. M. (1993). Patient preferences for non-steroidal anti-inflammatory drug related gastrointestinal complications and their prophylaxis. *Journal of Rheumatology, 20,* 358-361.

Refid: 122695

Main message:

- Among the adverse events associated with the use of non-steroidal anti-inflammatory drugs (NSAIDs), patients ranked surgery, hospitalization, and prophylaxis-induced diarrhea as the least desirable gastrointestinal (GI) complications.

Summary: This pilot study examined the preferences for avoiding adverse events that were associated with NSAID use. The results suggested that participants placed a high value on avoiding surgery, hospitalization, prophylaxis-induced diarrhea and uncomplicated ulcers. The avoidance of ulcer symptoms and the inconvenience of taking an additional medication for preventing GI complications four times daily appeared to be less important to these patients.

Garcia Popa-Lisseanu, M. G., Greisinger, A., Richardson, M., O'Malley, K. J., Janssen, N. M., Marcus, D. M., Tagore, J., & Suarez-Almazor, M. E. (2005). Determinants of treatment adherence in ethnically diverse, economically disadvantaged patients with rheumatic disease. *Journal of Rheumatology, 32*, 913-919.

Refid: 122724

Main message:

- The main barriers to adherence to treatment are fear of side effects, financial problems, difficulty in navigating the public health system, and perceived treatment inefficacy.

Summary: This study aimed to examine the factors that affect adherence to medical recommendations among ethnically diverse and economically disadvantaged patients with RA and systemic lupus erythematosus (SLE) in Houston, Texas. The majority of participants reported experiencing difficulty in adhering to their treatment. Patients with SLE or RA reported similar barriers to adhering to treatment and to keeping appointments. The authors concluded that patients' perceptions of, and experiences with, the health system influenced their adherence to treatment.

Jacobi, C. E., Triemstra, M., Rupp, I., Dinant, H. J., & van den Bos, G. A. (2001). Health care utilization among rheumatoid arthritis patients referred to a rheumatology center: unequal needs, unequal care? *Arthritis & Rheumatism, 45,* 324-330.
Refid: 123825
Main message:

- Most patients received the care they needed in the Netherlands; however, for older people with RA, there are problems with access to allied health care and psychosocial care.

Summary: A questionnaire survey was conducted among patients with RA in order to evaluate whether those in need of care actually received it. Health care use was assessed for medical care, allied health services, psychosocial counselling and home care. The results indicated that most patients received the care they needed. However, disease-related factors including age, sex and living situation were found to be predictive of the use of health services.

Kahn, K. L., MacLean, C. H., Liu, H., Rubenstein, L. Z., Wong, A. L., Harker, J. O., Chen, W. P., Fitzpatrick, D. M., Bulpitt, K. J., Traina, S. B., Mittman, B. S., Hahn, B. H., & Paulus, H. E. (2007). The complexity of care for patients with rheumatoid arthritis: metrics for better understanding chronic disease care. *Medical care, 45,* 55-65.
Refid: 123996
Main message:

- While patients with RA have frequent encounters with multiple providers, many also stop seeing a health professional possibly because of a lack of health care providers or because they only seek health professionals when they are needed urgently.

Summary: This prospective cohort study of 568 RA patients used observational data from telephone interviews to study health status, comorbidity, use of disease-modifying anti-rheumatic drugs, visits to care providers, provider types, encounter settings and the discontinuity between patients and providers. The results indicated that during a 12-month period patients on average saw three to four health care providers in the outpatient setting. Over the course of 24 months, 29% of patients changed their primary care provider and 15% changed their rheumatologist.

Kajiyama, H., Akama, H., Yamanaka, H., Shoji, A., Matsuda, Y., Tanaka, E., Nakajima, A., Terai, C., Hara, M., Tomatsu, T., Saitoh, T., & Kamatani, N. (2006). One third of Japanese patients with rheumatoid arthritis use complementary and alternative medicine. *Modern Rheumatology, 16,* 355-359.
Refid: 124000
Main message:

- Approximately 35% of patients with RA used CAM in Japan. Female patients and patients dissatisfied with DMARDs used CAM more frequently, regardless of their disease activity.

Summary: A cross-sectional descriptive study was performed using the database from a large observational cohort of RA patients. Among 3,815 RA patients 34.6% used at least one type of CAM. Health foods, including dietary supplements, were the most commonly used CAM. CAM was more frequently used by female patients. Sex and degree of satisfaction with DMARDs were significant independent predictive factors for CAM use.

Vetter, N. J., Charny, M., Lewis, P. A., & Farrow, S. (1990). Prevalence and treatment of symptoms of rheumatism and arthritis among over 65 year olds: a community profile. *British Journal of General Practice, 40,* 69-71.
Refid: 115220
Main message:

- Arthritis and rheumatism are common among people aged 65 years and over, especially in women, but many people with symptoms had not reported them to a health professional.

Summary: This survey involved a random sample of 712 people aged 65 years and over in the UK. Symptoms of arthritis and rheumatism were very common, more so in women than in men, and were associated with marked degrees of disability and some dependency. While most respondents regarded their general practitioner as the best person to treat such symptoms, many had not reported them to any health service personnel, but had chosen instead to treat them themselves, suggesting a degree of skepticism about the effectiveness of professional treatment.

Wolfe, F. & Michaud, K. (2007). Resistance of rheumatoid arthritis patients to changing therapy: discordance between disease activity and patients' treatment choices. *Arthritis & Rheumatism, 56,* 2135-2142.
Refid: 129007
Main messages:

- There is a substantial discrepancy between patients' satisfaction with therapy and RA disease activity and functional status.
- Fear of losing control of one's health and fear of side effects are major concerns of people with RA. Maintaining the current status, rather than aiming for future improvement, appears to be a higher priority for patients.

Summary: In this study, a questionnaire was administered to 6,135 people with RA. The results showed that 63.8% of the patients would not want to change their treatment as long as their condition did not deteriorate, 77.3% were satisfied with their medications and 9.4% were dissatisfied. These assessments were weakly related to RA activity and functional status. Predictors of unwillingness to change therapy were satisfaction with RA control, risk of side effects, physician opinion, fear of loss of control, lack of better medications, and costs. There was little difference in results between patients who were receiving biologic agents and those who were not.

Rheumatoid arthritis: Allied Health – qualitative studies (N=9)

Anonymous. On living with rheumatoid arthritis (1991). *Medical Journal of Australia, 155,* 268-269.
Refid: 120064
Main messages:

- Living with arthritis is difficult both physically and mentally.
- Different treatments produce different side effects. Emotional support is very important to help patients cope with both the disease and the side effects of treatments.

Summary: This article is a narrative by a patient who has lived with rheumatoid arthritis (RA) for over 20 years. The patient described the different treatment options she has tried both successfully and unsuccessfully to manage her arthritis. There is a discussion about the physical treatment options as well as the emotional and psychological treatment options to help with self-esteem and motivation issues. The need for emotional support is intense, but the patient often finds it difficult to seek out support because he or she is feeling low when the disease is at its most debilitating.

Ashe, B., Taylor, M., & Dubouloz, C. (2005). The process of change: listening to transformation in meaning perspectives of adults in arthritis health education groups. *Canadian Journal of Occupational Therapy, 72,* 280-288.
Refid: 110204
Main message:

- Education groups may facilitate the adoption of healthy behaviours in people with arthritis.

Summary: This study used qualitative interviews to explore patients' experiences in two different arthritis education groups to develop an understanding of meaningful group experiences. Ten participants with RA or other inflammatory arthritis were recruited. Individual and focus group interviews provided descriptions of experiences. The results showed that arthritis education group experiences led to improved perceptions of an ability to cope with the chronic disease. The idea that the patient's process of change can lead to healthy behaviours and desired health outcomes was also discussed.

Barlow, J. H., Cullen, L. A., & Rowe, I. F. (2002). Educational preferences, psychological well-being and self-efficacy among people with rheumatoid arthritis. *Patient Education & Counseling, 46,* 11-19.
Refid: 110302
Main messages:

- Education on the disease, treatments and emotional issues should be conducted on a one-to-one basis.
- Some patients with RA prefer group interventions for learning about self-management and exercise.

Summary: This mixed method design examined patients' preferences for interventions, as well as psychological well-being and self-efficacy. It examined addressing education, self-management and the consequences of RA. The results revealed that patients preferred education about the disease and its treatment, as well as emotional issues, to be delivered on a one-to-one basis by health professionals. Group interventions were the preferred format for self-management, exercise and relationship issues, whereas videos were thought to be useful for demonstrating the use of aids and showing how other families cope. The status of both physical and psychological health were correlated with arthritis self-efficacy.

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness, 4,* 167-182.
Refid: 110721
Main message:

- Chronically ill people can make adaptations to their lifestyle, but may have moments when they feel helpless, such as when symptoms are severe or following surgery.

Summary: The study used semi-structured qualitative interviews with patients with RA to describe the experience of onset and development of RA. The results highlighted the resources (cognitive and material) available to individuals, modes of explanation for pain and suffering, and factors that help explain variation in experience.

Dyck, I. (1992). Managing chronic illness: an immigrant woman's acquisition and use of health care knowledge. *American Journal of Occupational Therapy, 46,* 696-705.
Refid: 122122
Main message:

- For occupational therapy, careful consideration needs to be made about the social and economic circumstances of the client's life, especially for those who are disadvantaged.

Summary: This case study illustrated the role of family, community networks and workplace in the management of RA from the perspective of a Chinese-Canadian immigrant woman. Occupational therapy in a clinical setting was indentified as an important component in the management of her conditions. It showed how health care decisions were related to her life as a working-class immigrant woman.

Hewlett, S., Cockshott, Z., Byron, M., Kitchen, K., Tipler, S., Pope, D., & Hehir, M. (2005). Patients' perceptions of fatigue in rheumatoid arthritis: overwhelming, uncontrollable, ignored. *Arthritis & Rheumatism (Arthritis Care & Research), 53,* 697-702.
Refid: 123484
Main message:

- Fatigue associated with RA is significant, intrusive and overwhelming, and patients may struggle to manage it alone without adequate support.

Summary: This qualitative study interviewed 15 patients with RA about their experience in managing fatigue. Participants described two types of fatigue: severe weariness and dramatic overwhelming fatigue. RA fatigue was found to be extreme, unfounded and non-resolving. Participants described the physical, cognitive and emotional impact of feeling fatigued, and the effects on relationships and participation in social and family roles. They attributed fatigue to the inflammatory process, overuse of the joints and unrefreshing sleep. Participants used self-management strategies but with limited success. Most did not discuss fatigue with clinicians but when they did, they felt it was dismissed. Some participants held negative views on the management of fatigue due to limited success with their self-management strategies and limited guidance from health professionals, and a resulting perceived lack of control over their fatigue.

Iaquinta, M. L. & Larrabee, J. H. (2004). Phenomenological lived experience of patients with rheumatoid arthritis. *Journal of nursing care quality, 19,* 280-289.
Refid: 123721

Main message:

- Nurse practitioners can help people with RA deal with challenges they experience to help improve their quality of life.

Summary: This qualitative study explored: (1.) the lived experience of RA from the perspective of the patient, (2.) the patient's view of the nurse's role and (3.) the patient's role as co-manager of RA. The purposive sample consisted of six Caucasian women living in West Virginia. The results showed six emerging themes: grieving, understanding RA symptoms, the importance of resilience, confronting negative feelings, understanding how to use the health care system and gaining new perspectives on life. The quality of nursing care can be improved by providing personalized, holistic and humanistic care, which can ultimately contribute to an improved quality of life for the patient.

Nyman, C. S. & Lutzen, K. (1999). Caring needs of patients with rheumatoid arthritis. *Nursing science quarterly, 12,* 164-169.
Refid: 125910
Main message:

- Interviews with people with RA revealed four predominant themes: seeking help, searching for meaning, uncertainty and fear of being disappointed. These four issues captured the complexities of the physical, emotional, social and existential experiences of the patients.

Summary: Qualitative interviews were conducted in order to identify the caring needs specific to the human experience of having RA and undergoing acupuncture treatment. With the application of Watson's 10 Carative Factors, four themes related to the caring needs of patients with RA who sought acupuncture were identified. These patients have a strong tendency toward and need for seeking help. They are searching for meaning within the context of a chronic disease, and they are coping with the uncertainty and fear of being disappointed because of the chronic aspects of the disease. These needs affect and are affected by the physical, emotional, social and existential events of their lives. Awareness of them by the nurse-acupuncturist will allow him or her to be more aware of the caring needs of these patients.

Sakalys, J. A. (1997). Illness behavior in rheumatoid arthritis. *Arthritis Care and Research, 10,* 229-237.
Refid: 126924
Main message:

- An interview study of women with RA showed that the illness is prolonged, diagnosis and treatment are confusing and dealing with RA causes personal and social stress.

Summary: In this descriptive study, interview and medical records data from 50 female patients were analyzed using quantitative and qualitative techniques. The findings revealed a high incidence of symptom normalization, self-treatment, symptom comparison and delays in diagnosis with multiple misdiagnoses and several physicians being consulted. Most participants reported a lack of validation from their health care providers about the initial symptoms, emotional distress and relief upon receiving an accurate diagnosis. Significant associations were found; for example, (1.) illness-related symptom attributions were associated with fewer physicians consulted and with less invalidation; (2.) life stress events were associated with fewer physicians consulted and with a faster diagnosis; and (3.) remissions were associated with time to diagnosis, the number of physicians consulted and the number of misdiagnoses.

Rheumatoid arthritis: Allied Health – quantitative studies (N=17)

Berkanovic, E. & Hurwicz, M. L. (1995). Physician visits by rheumatoid arthritis patients: a prospective analysis. *Arthritis Care & Research, 8,* 73-79.
Refid: 120705
Main message:

- Variations in the types of physician visits by people with RA are related to both predisposing and enabling factors.

Summary: The purpose of this quantitative study was to examine patient-initiated physician visits, physician-requested visits and visits for disease flares by patients with RA. The results demonstrated that predisposing and enabling factors accounted for 50–67% of the explained variance in the three types of visits, while need accounted only for 33–50%. These results showed the need for further studies on the factors that influence both RA patients' decisions to seek care and physicians' decisions to request further visits.

Berkanovic, E., Hurwicz, M. L., & Batchlor, E. (1991). Rheumatoid arthritis and the use of medical services. *Arthritis Care & Research, 4*, 12-21.
Refid: 120707
Main message:

- The use of medical services by patients with RA is not a simple function of need.

Summary: This quantitative study analyzed the factors that are associated with the use of services among patients with RA. The data was derived from interviews with patients with RA. The results showed that predisposing variables such as age, sex, marital status, race and education, as well as enabling variables such as income and whether the patient with arthritis had health insurance, were related to service use.

Brekke, M., Hjortdahl, P., & Kvien, T. K. (2001). Involvement and satisfaction: A Norwegian study of health care among 1,024 patients with rheumatoid arthritis and 1,509 patients with chronic noninflammatory musculoskeletal pain. *Arthritis Care and Research, 45,* 8-15.
Refid: 120991
Main messages:

- A high level of education and contact with a rheumatologist are associated with a high level of health care involvement by the patient.
- High involvement and good mental health are associated with patient satisfaction with health care.

Summary: The purpose of this survey was to investigate involvement in and satisfaction with health care among patients with RA. The objective was to identify target areas for improvement. Being young, well educated, physically disabled, in good mental health and self-efficient correlated with a high level of involvement in health care. Satisfaction with health care was higher for patients who were female, had a low pain level, had good mental health and reported high self-efficacy.

Buckley, L. M., Vacek, P., & Cooper, S. M. (1990). Educational and psychosocial needs of

patients with chronic disease: a survey of preferences of patients with rheumatoid arthritis. *Arthritis Care and Research, 3,* 5-10.
Refid: 121143
Main messages:

- Patients with RA have identified their most important issues as being good communication with the doctor, understanding their medication and dealing with their pain.
- Patients with RA are also concerned about the effects of arthritis on their quality of life.

Summary: This quantitative study surveyed patients with RA about the importance of psychosocial and educational issues, and asked them how they wished to receive help. The study examined individual variables, including sex, age, disease duration and disease severity, and their relationships to patients' choices. The issues rated most important by patients included communicating with the doctor; understanding their medication; dealing with their pain; and the effects of arthritis on their energy level, their participation at work and their future. Most patients preferred to seek help from their physicians, although many were willing to attend groups or see non-physician counsellors for individual counselling.

Cardiel, M. H. & Rojas-Serrano, J. (2002). Community-based study to estimate prevalence, burden of illness and help seeking behavior in rheumatic diseases in Mexico City. A COPCORD study. *Clinical & Experimental Rheumatology, 20,* 617-624.
Refid: 110792
Main message:

- A general practitioner treated 72% of patients with rheumatic diseases in Mexico City. Most patients responded well to the prescribed medication.

Summary: The purpose of this study was to estimate the prevalence of rheumatic diseases in a suburban community in Mexico City. The burden of illness and help-seeking behaviour of patients with rheumatic diseases were also examined. The results indicated that 419 participants (17%) had reported pain in the last seven days due to musculoskeletal disorders and 13% of the total sample had experienced some form of treatment.

Centers for Disease Control and Prevention (CDC) (2003). Adults who have never seen a health-care provider for chronic joint symptoms--United States, 2001. *MMWR - Morbidity & Mortality Weekly Report, 52,* 416-419.
Refid: 110828
Main message:

- One in five people with chronic joint symptoms are not seeking treatment for their joint symptoms.

Summary: The purpose of this CDC report was to estimate the prevalence of people with chronic joint symptoms who did not see a health care provider in 2001. The results indicated that one-fifth of the estimated population had never seen a health care provider for joint pain problems. Several factors contribute to these findings. For example, many patients have comorbidities that were more severe or life-threatening then their joint symptoms and so they might pay less attention to the latter. Also, some patients perceived arthritis as being part of the normal aging process and so felt that treatment was neither necessary nor beneficial.

Cho, K. J., Jang, S. H., Lee, S. K., & Doh, W. S. (1998). Utilization characteristics of health care

service for rheumatoid arthritis patients in Korea. *Yonsei medical journal, 39,* 247-251.
Refid: 121456
Main messages:

- Patients with RA in Korea take longer to consult a medical doctor compared to patients with RA in the United States.
- One factor that contributes to this lag time includes the use of unconventional medicine (Chinese herbal medicine) or non-prescribed medicine after symptom onset.

Summary: The purpose of this study was to determine the factors responsible for delaying diagnosis and optimal management of RA in Korea. From the study sample of 98 patients, 51 patients consulted an orthopaedic surgeon, 19 patients consulted a Chinese herbal doctor and 16 patients consulted a pharmacist. In this study 59% of patients were diagnosed with RA by an orthopaedic surgeon, and 25% by a rheumatologist. Patients with RA in Korea lost twice as much time when consulting a medical doctor compared to patients with RA in the United States.

Garcia Popa-Lisseanu, M. G., Greisinger, A., Richardson, M., O'Malley, K. J., Janssen, N. M., Marcus, D. M., Tagore, J., & Suarez-Almazor, M. E. (2005). Determinants of treatment adherence in ethnically diverse, economically disadvantaged patients with rheumatic disease. *Journal of Rheumatology, 32,* 913-919.
Refid: 122724
Main message:

- The main barriers to adherence to treatment are fear of side effects, financial problems, difficulty in navigating the public health system, and perceived treatment inefficacy.

Summary: This study aimed to examine the factors that affect adherence to medical recommendations among ethnically diverse and economically disadvantaged patients with RA and systemic lupus erythematosus (SLE) in Houston, Texas. The majority of participants reported experiencing difficulty in adhering to their treatment. Patients with SLE or RA reported similar barriers to adhering to treatment and to keeping appointments. The authors concluded that patients' perceptions of, and experiences with, the health system influenced their adherence to treatment.

Hughes, R. A., Carr, M. E., Huggett, A., & Thwaites, C. E. (2002). Review of the function of a telephone helpline in the treatment of outpatients with rheumatoid arthritis. *Annals of the Rheumatic Diseases, 61,* 341-345.
Refid: 123662
Main messages:

- Clinical advice and support can be provided by a rheumatology helpline set up as an adjunct to a standard outpatient service.
- Helpline services can improve the quality of care provided by an outpatient department and provide benefits to a social insurance health care system.

Summary: To assess patient satisfaction a postal questionnaire was sent to 87 patients who called the rheumatology helpline in a one-month period. The results indicated that 97% of the participants were satisfied with the response time and 100% were satisfied with the courtesy; 95% and 98% felt that their questions were answered directly and to their satisfaction, respectively. Had the helpline not been available, 60% of the patients would have made an appointment with their GP. The helpline produced a cost saving to the National Health Service, largely due to the GP consultations avoided.

Jacobi, C. E., Triemstra, M., Rupp, I., Dinant, H. J., & van den Bos, G. A. (2001). Health care utilization among rheumatoid arthritis patients referred to a rheumatology center: unequal needs, unequal care? *Arthritis & Rheumatism, 45,* 324-330.
Refid: 123825
Main message:

- Most patients received the care they needed in the Netherlands; however, for older people with RA, there are problems with access to allied health care and psychosocial care.

Summary: A questionnaire survey was conducted among patients with RA in order to evaluate whether those in need of care actually received it. Health care use was assessed for medical care, allied health services, psychosocial counselling and home care. The results indicated that most patients received the care they needed. However, disease-related factors including age, sex and living situation were found to be predictive of the use of health services.

Kahn, K. L., MacLean, C. H., Liu, H., Rubenstein, L. Z., Wong, A. L., Harker, J. O., Chen, W. P., Fitzpatrick, D. M., Bulpitt, K. J., Traina, S. B., Mittman, B. S., Hahn, B. H., & Paulus, H. E. (2007). The complexity of care for patients with rheumatoid arthritis: metrics for better understanding chronic disease care. *Medical care, 45,* 55-65.
Refid: 123996
Main message:

- While patients with RA have frequent encounters with multiple providers, many also stop seeing a health professional possibly because of a lack of health care providers or because they only seek health professionals when they are needed urgently.

Summary: This prospective cohort study of 568 RA patients used observational data from telephone interviews to study health status, comorbidity, use of disease-modifying anti-rheumatic drugs, visits to care providers, provider types, encounter settings and the discontinuity between patients and providers. The results indicated that during a 12-month period patients on average saw three to four health care providers in the outpatient setting. Over the course of 24 months, 29% of patients changed their primary care provider and 15% changed their rheumatologist.

Kjeken, I., Dagfinrud, H., Mowinckel, P., Uhlig, T., Kvien, T. K., & Finset, A. (2006). Rheumatology care: Involvement in medical decisions, received information, satisfaction with care, and unmet health care needs in patients with rheumatoid arthritis and ankylosing spondylitis. *Arthritis & Rheumatism, 55,* 394-401.
Refid: 124337
Main message:

- There is a need for a more flexible and patient-centred care model in which patients with RA or ankylosing spondylitis can decide which services they need and how they should be delivered.

Summary: Questionnaires were completed by 1,193 patients with RA and ankylosing spondylitis. The majority of patients reported medium to high levels of information received about RA, involvement in medical decisions and satisfaction with care. High involvement in medical decisions was associated with high levels of perceived information and satisfaction, as well as with lower age and a good health status. Patient satisfaction, a high level of received information, age and 12+ years of formal education were significant predictors to current involvement. Nearly one-third of the respondents reported a variety of unmet health care needs, and this report was associated with poor health.

Martin, L. J. & Griffith, S. M. (2006). High disease activity scores predict the need for additional health services in patients over 60 with rheumatoid arthritis. *Musculoskeletal Care, 4,* 1-11.
Refid: 125245
Main message:

- A survey of people attending rheumatology outpatient clinics indicated that there was significant unmet demand for chiropody and footwear, education about RA, physiotherapy, occupational therapy and surgery.

Summary: A cross-sectional survey was conducted of 123 patients aged 60 years and over attending rheumatology outpatient clinics. Respondents were more likely to express a need for chiropody or footwear, physiotherapy or education about RA than for occupational therapy or surgery. Those respondents who had high disease activity scores and high anxiety scores showed a greater perceived need for additional health services.

McCabe, C., McDowell, J., Cushnaghan, J., Butts, S., Hewlett, S., Stafford, S., O'Hea, J., & Breslin, A. (2000). Rheumatology telephone helplines: an activity analysis. South and West of England Rheumatology Consortium. *Rheumatology, 39,* 1390-1395.
Refid: 125332
Main message:

- Rheumatology helpline services in the UK lacked uniformity in the delivery of care and accessibility to relevant patient groups. These differences could result in patient dissatisfaction and confusion, and the creation of national guidelines is recommended.

Summary: Information was collected on the first 100 calls received by six rheumatology helplines in the south and west of England. Background information was gathered on the management, availability, setting and purpose of each helpline. The results indicated that patients with RA were the major users and no significant differences were found in the outcome of their calls between centres, although wide variations were found in the operation of the helplines, the populations they serve and the services they offer.

Ramos-Remus, C., Watters, C. A., Dyke, L., Suarez-Almazor, M. E., & Russell, A. S. (1999). Assessment of health locus of control in the use of nonconventional remedies by patients with rheumatic diseases. *Journal of Rheumatology, 26,* 2468-2474.
Refid: 126582
Main message:

- Over half of respondents used nonconventional remedies (NCR) for their RA symptoms, but fewer than 2 in 10 told their rheumatologist about them. NCR users tend to be younger, more disabled and in the middle income class.

Summary: A cross-sectional survey and qualitative interview of 200 patients with rheumatic diseases in Edmonton, Canada, was conducted to evaluate the prevalence of use, and patients' beliefs, perceptions and expectations in relation to NCR. The results showed that 60% of the study patients had used NCR in the previous 12 months, 47% had received at least one NCR before the first rheumatology consultation and an additional 8% initiated NCR after their initial contact with a rheumatologist. Only 18% of the patients using NCR notified their rheumatologist about their use. Patients who used NCR in the preceding 12 months were younger, slightly more disabled and in the middle income class.

Riemsma, R. P., Klein, G., Taal, E., Rasker, J. J., Houtman, P. M., van Paassen, H. C., & Wiegman, O. (1998). The supply of and demand for informal and professional care for patients with rheumatoid arthritis. *Scandinavian journal of rheumatology, 27,* 7-15.
Refid: 126708
Main message:

- The amount of help received by patients with RA is related to the physical condition of the patient, marital status of the patient and sex of the caregiver.

Summary: A survey of patients with RA and their caregivers found that in general patients received the help they needed. Most help given at home was provided by informal caregivers such as friends and family of the patient. The amount of help received from informal caregivers is largely explained by the patient's physical condition and marital status, the sex of the caregiver, the patient's expectations of their ability to cope with RA and the age of the patient. The amount of help received from health professionals is related primarily to the marital status and physical condition of the patient.

Saag, K. G., Doebbeling, B. N., Rohrer, J. E., Kolluri, S., Mitchell, T. A., & Wallace, R. B. (1998). Arthritis health service utilization among the elderly: The role of urban-rural residence and other utilization factors. *Arthritis Care and Research, 11,* 177-185.
Refid: 126901
Main message:

- There is a consistent association of need factors, joint swelling and a diagnosis of RA with physician utilization. Urban/rural status does not appear to independently influence the use of health care providers for arthritis care.

Summary: A population-based telephone interview survey was conducted on a random sample of 488 adults aged 65 or older with self-reported arthritis, with about half the sample from urban communities and half from rural communities. The results indicated that urban respondents were more commonly reported as having received a diagnosis of osteoarthritis from their physicians but being less likely to report RA. A greater proportion of urban versus rural respondents had seen a physician for their arthritis and had seen an orthopaedist or general internist more often. Some factors were significantly associated with prior rheumatologist use; for example, diagnosis of RA, being younger, living with someone, having a higher income and being further from an arthritis care provider.

Rheumatoid arthritis: CAT – qualitative studies (N=6)

Marines Castillo, A. L., Salcido, G. P., Orozco, C., Osorio, C. M. (2000). Interes del paciente con artritis reumatoide por aprender acerca de la enfermedad. *Rev Mex Rheumat 15(5),* 131 – 6.
Refid: 320763
Main Message:

- People with RA are interested in knowing more about the disease, especially with respect to diet and exercise. The main source of information is newspapers.

Summary: In this study, a questionnaire was administered to 52 ambulatory patients (44 women

and 8 men) with rheumatoid arthritis. The questionnaire involved four areas: general data, patients' interest for information concerning RA, popular concepts, and functional consequences of RA. A high interest was shown for knowing more about the disease, the main source of information was newspapers, and the most important items were diet and physical exercise. Medical information was received only by exception. Patients did not agree with the possibility of a cure, they did not believe the disease was contagious, and they did not believe that it occurred in children. Patients were instead convinced of a cause-effect relationship in which RA was caused by cold and temperature changes. They also believed that the disease can be controlled, believed in the concept of arthritis as a group of different diseases, and believed that it was possible to lead an active life despite the disease. Having an interest in knowing more about the disease was clearly related to better functioning and a higher schooling degree.
**This article is in Spanish*

Chan, H. (2002). The utilization and reasons of choice for Chinese or western medicine among rheumatoid arthritis patients in Hong Kong. *Hong Kong Nursing Journal, 38,* 7-16.
Refid: 121384
Main message:

- In Hong Kong, patients' beliefs in Chinese and Western medicine, the cost of treatments and the effects of treatments are associated with treatment preferences and use.
- Chinese medicine is often used because a friend or relative recommends it and Western medicine is often used because a physician recommends it.

Summary: This mixed method study examined the utilization pattern and reasons for patients with RA using Chinese and/or Western medicine. Most patients used Chinese medicine because it was recommended by a friend or relative, and most of those who used Western medicine were acting on the recommendations of physicians.

Dyck, I. (1992). Managing chronic illness: an immigrant woman's acquisition and use of health care knowledge. *American Journal of Occupational Therapy, 46,* 696-705.
Refid: 122122
Main message:

- For occupational therapy, careful consideration needs to be made about the social and economic circumstances of the client's life, especially for those who are disadvantaged.

Summary: This case study illustrated the role of family, community networks and workplace in the management of RA from the perspective of a Chinese-Canadian immigrant woman. Occupational therapy in a clinical setting was indentified as an important component in the management of her conditions. It showed how health care decisions were related to her life as a working-class immigrant woman.

Nyman, C. S. & Lutzen, K. (1999). Caring needs of patients with rheumatoid arthritis. *Nursing science quarterly, 12,* 164-169.
Refid: 125910
Main message:

- Interviews with people with RA revealed four predominant themes: seeking help, searching for meaning, uncertainty and fear of being disappointed. These four issues captured the complexities of the physical, emotional, social and existential experiences of the patients.

Summary: Qualitative interviews were conducted in order to identify the caring needs specific to the human experience of having RA and undergoing acupuncture treatment. With the application of Watson's 10 Carative Factors, four themes related to the caring needs of patients with RA who sought acupuncture were identified. These patients have a strong tendency toward and need for seeking help. They are searching for meaning within the context of a chronic disease, and they are coping with the uncertainty and fear of being disappointed because of the chronic aspects of the disease. These needs affect and are affected by the physical, emotional, social and existential events of their lives. Awareness of them by the nurse-acupuncturist will allow him or her to be more aware of the caring needs of these patients.

Rao, J. K., Arick, R., Mihaliak, K., & Weinberger, M. (1998). Using focus groups to understand arthritis patients' perceptions about unconventional therapy. *Arthritis Care & Research, 11,* 253-260.
Refid: 114120
Main message:

- Patients with OA and RA would use unconventional therapies (UT) to relieve pain. The source of information about UT is important, but cost is not.

Summary: Focus groups of randomly selected patients with arthritis, four groups of RA patients and one group of OA patients, each containing 20–30 people, were conducted to discuss their beliefs about arthritis and UT. All the participants believed arthritis to be incurable by conventional regimens or UT. Over half the participants had used UT to relieve pain despite the cost. Patients trusted information about UT from family, friends and others with arthritis, but not information from supermarket tabloids or television commercials. Most discussed UT use with their physician, primarily to prevent interactions with prescribed treatments. Physicians' reactions ranged from ridicule to giving permission to continue using UT.

Rose, G. (2006). Why do patients with rheumatoid arthritis use complementary therapies? *Musculoskeletal Care, 4,* 101-115.
Refid: 126798
Main message:

- Compared to conventional treatments, complementary therapy (CT) is perceived to have fewer adverse reactions, provide greater selections, provide psychological comfort and provide good working relationships between patients and their CT therapists.

Summary: This qualitative study aimed to develop an understanding of the lived experience of patients with RA. Incentives to use CT included dissatisfaction with conventional treatment, social factors and psychological issues such as depression, hopelessness and fear. Perceived benefits of CT included improved physical and psychological functioning. The most commonly used CTs were herbal remedies and supplements, closely followed by aromatherapy massage. Disadvantages and risks were identified as physical (pain and discomfort), psychological (fear and uncertainty) and/or material (cost).

Rheumatoid arthritis: CAT – quantitative studies (N=11)

Breuer, G. S., Orbach, H., Elkayam, O., Berkun, Y., Paran, D., Mates, M., & Nesher, G. (2006). Use of complementary and alternative medicine among patients attending rheumatology clinics in Israel. *Israel Medical Association Journal, 8,* 184-187.
Refid: 121014
Main messages:

- Complementary and alternative medicine (CAM) use was influenced by the level of education of the patient.
- Patients with RA are less likely than others with rheumatic diseases to use CAM.
- The preferred method of CAM among patients with rheumatic diseases mirrors that of the general population, and is not specific to those with rheumatic diseases.

Summary: The objective of this quantitative study was to evaluate the prevalence of CAM use among patients with rheumatic diseases, and to analyze the demographic features of CAM users, their reasons for using CAM and the use of specific CAM methods. The results indicated that 42% of patients reported using CAM. Homeopathy and acupuncture were the most common types of CAM treatment used. CAM was more commonly used by patients with advanced education. Patients with RA used CAM less than patients with other rheumatologic conditions.

Buchbinder, R., Gingold, M., Hall, S., & Cohen, M. (2002). Non-prescription complementary treatments used by rheumatoid arthritis patients attending a community-based rheumatology practice. *Internal Medicine Journal, 32,* 208-214.
Refid: 121130
Main messages:

- Complementary treatment use is prevalent among patients with RA who attend a community-based private rheumatology practice.
- Patients spent as much money on complementary medicine (CM) as they did on prescription medicine.

Summary: The research used quantitative questionnaires to determine the prevalence and features of CM use among patients with RA who attended a community-based private rheumatology practice. The results showed that nearly two-thirds of the patients who were surveyed had used some form of CM in the past year. The most commonly used treatments were dietary and behavioural and cognitive therapies. Prescription medicine was considered more beneficial than either form of CM, and both users and non-users of CM had a similar perception of the efficacy of prescription medicine. Women and patients not in receipt of a pension were the most likely to have consulted a CM practitioner.

Cardiel, M. H. & Rojas-Serrano, J. (2002). Community-based study to estimate prevalence, burden of illness and help seeking behavior in rheumatic diseases in Mexico City. A COPCORD study. *Clinical & Experimental Rheumatology, 20,* 617-624.
Refid: 110792
Main message:

- A general practitioner treated 72% of patients with rheumatic diseases in Mexico City. Most patients responded well to the prescribed medication.

Summary: The purpose of this study was to estimate the prevalence of rheumatic diseases in a suburban community in Mexico City. The burden of illness and help-seeking behaviour of patients with rheumatic diseases were also examined. The results indicated that 419 participants

(17%) had reported pain in the last seven days due to musculoskeletal disorders and 13% of the total sample had experienced some form of treatment.

Chandola, A., Young, Y., McAlister, J., & Axford, J. S. (1999). Use of complementary therapies by patients attending musculoskeletal clinics. *Journal of the Royal Society of Medicine, 92,* 13-16.
Refid: 121395
Main message:

- There is a substantial use of complementary therapy in patients attending musculoskeletal disease clinics.

Summary: The focus of this study was to determine the prevalence of complementary therapies among patients attending a musculoskeletal clinic. The predominant diagnosis was RA. Over half the patients were satisfied with conventional medical treatment and 38% had considered the use of complementary therapies. The majority of patients who had used complementary therapies said they had enjoyed some benefit. Acupuncture, homoeopathy, osteopathy and herbal medicine were the most popular types of treatment used. Female patients and those who were dissatisfied with current therapies were most likely to have considered complementary therapies.

Chandrashekara, S., Anilkumar, T., & Jamuna, S. (2002). Complementary and alternative drug therapy in arthritis. *Journal of the Association of Physicians of India, 50,* 225-227.
Refid: 121397
Main message:

- Of the patients with RA in this study, which took place in India, 43% used complementary and alternative medicine (CAM) drugs for the treatment of arthritis.

Summary: This study aimed to understand the pattern of therapy and medication used by patients with RA. The results showed that almost half the patients had used CAM drugs. Ayurveda and homeopathy were the two most common CAM used by the patients. The majority of participants believed that conventional medicine could not cure RA, and that adverse reactions were rare in CAM. These factors predominantly influenced their decisions to choose CAM. The use of CAM increased as the duration of the disease increased.

Cho, K. J., Jang, S. H., Lee, S. K., & Doh, W. S. (1998). Utilization characteristics of health care service for rheumatoid arthritis patients in Korea. *Yonsei medical journal, 39,* 247-251.
Refid: 121456
Main messages:

- Patients with RA in Korea take longer to consult a medical doctor compared to patients with RA in the United States.
- One factor that contributes to this lag time includes the use of unconventional medicine (Chinese herbal medicine) or non-prescribed medicine after symptom onset.

Summary: The purpose of this study was to determine the factors responsible for delaying diagnosis and optimal management of RA in Korea. From the study sample of 98 patients, 51 patients consulted an orthopaedic surgeon, 19 patients consulted a Chinese herbal doctor and 16 patients consulted a pharmacist. In this study 59% of patients were diagnosed with RA by an orthopaedic surgeon, and 25% by a rheumatologist. Patients with RA in Korea lost twice as much time when consulting a medical doctor compared to patients with RA in the United States.

Cronan, T. A., Kaplan, R. M., & Kozin, F. (1993). Factors affecting unprescribed remedy use among people with self-reported arthritis. *Arthritis Care and Research, 6,* 149-155.
Refid: 121717
Main message:

- Unprescribed remedies are frequently used by patients with arthritis, and are rated by patients as effective as prescribed remedies.

Summary: The purpose of this study was to determine the frequency and consequences of use of unprescribed remedies by people with self-reported osteoarthritis, and to identify factors that predict such use. Of the 382 participants with self-reported musculoskeletal disorders involved, the results showed that 84% had used at least one unprescribed remedy during the past six months. People with self-reported RA used more such remedies than those with self-reported osteoarthritis, and those with a greater degree of disability used more unprescribed remedies than those who were less affected.

Jacobs, J. W. G., Kraaimaat, F. W., & Bijlsma, J. W. (2001). Why do patients with rheumatoid arthritis use alternative treatments? *Clinical rheumatology, 20,* 192-196.
Refid: 123834
Main message:

- Investigators concluded that psychosocial differences accounted for the use of alternative treatments in patients with RA.

Summary: In this survey, 266 patients with RA were randomly selected from hospitals in the Netherlands to provide information about health and symptom status. The results indicated that female patients used alternative treatments more often than male patients did. With males and females combined, those who used alternative treatments were younger than those who did not. While the patient groups did not differ in terms of medical visits, those who used alternative treatments visited medical specialists for RA-related complaints less frequently than those who relied only on conventional treatments. Investigators concluded that those people who perceive their RA symptoms to be worse without having a worsening of the disease could explain why some patients use CM. This suggests that CM can be substituted not by additional conventional treatment prescribed by the rheumatologist, but rather by psychosocial intervention.

Kajiyama, H., Akama, H., Yamanaka, H., Shoji, A., Matsuda, Y., Tanaka, E., Nakajima, A., Terai, C., Hara, M., Tomatsu, T., Saitoh, T., & Kamatani, N. (2006). One third of Japanese patients with rheumatoid arthritis use complementary and alternative medicine. *Modern Rheumatology, 16,* 355-359.
Refid: 124000
Main message:

- Approximately 35% of patients with RA used CAM in Japan. Female patients and patients dissatisfied with DMARDs used CAM more frequently, regardless of their disease activity.

Summary: A cross-sectional descriptive study was performed using the database from a large observational cohort of RA patients. Among 3,815 RA patients 34.6% used at least one type of CAM. Health foods, including dietary supplements, were the most commonly used CAM. CAM was more frequently used by female patients. Sex and degree of satisfaction with DMARDs were significant independent predictive factors for CAM use.

Kay, E. A. & Punchak, S. S. (1988). Patient understanding of the causes and medical treatment of rheumatoid arthritis. *British journal of rheumatology, 27,* 396-398.
Refid: 124175
Main message:

- Patients generally perceive themselves as having little understanding about the cause and treatment of RA, and want more information about their disease and its management.

Summary: Qualitative interviews were conducted with 100 RA patients to assess their knowledge of the disease and its treatment. Only 46 patients said they had received information about RA from health care professionals. The most popular source of information used by the patients was television (82%). Patients believed that a number of factors caused RA and subsequent flare-ups. These included stress, too much exercise, infections and climate. Patients' knowledge of symptoms was also poor. Fifty-eight patients had tried non-prescribed remedies for RA, but 70% did not find them effective.

Ramos-Remus, C., Watters, C. A., Dyke, L., Suarez-Almazor, M. E., & Russell, A. S. (1999). Assessment of health locus of control in the use of nonconventional remedies by patients with rheumatic diseases. *Journal of Rheumatology, 26,* 2468-2474.
Refid: 126582
Main message:

- Over half of respondents used nonconventional remedies (NCR) for their RA symptoms, but fewer than 2 in 10 told their rheumatologist about them. NCR users tend to be younger, more disabled and in the middle income class.

Summary: A cross-sectional survey and qualitative interview of 200 patients with rheumatic diseases in Edmonton, Canada, was conducted to evaluate the prevalence of use, and patients' beliefs, perceptions and expectations in relation to NCR. The results showed that 60% of the study patients had used NCR in the previous 12 months, 47% had received at least one NCR before the first rheumatology consultation and an additional 8% initiated NCR after their initial contact with a rheumatologist. Only 18% of the patients using NCR notified their rheumatologist about their use. Patients who used NCR in the preceding 12 months were younger, slightly more disabled and in the middle income class.

Rheumatoid arthritis: Surgery – quantitative studies (N=3)

Chung, K. C., Kotsis, S. V., Kim, H. M., Burke, F. D., & Wilgis, E. F. (2006). Reasons why rheumatoid arthritis patients seek surgical treatment for hand deformities. *Journal of Hand Surgery - American Volume, 31,* 289-294.
Refid: 121509
Main message:

- Functional disability and pain were the main reasons why people with RA had surgery for hand deformities.

Summary: The purpose of this study was to determine the importance of function, pain, and aesthetics in patients' decisions to have metacarpophalangeal (MCP) joint arthroplasty for hand deformities. The results showed that patients with less function and greater pain were more likely to choose MCP joint arthroplasty. Other factors associated with an increased likelihood for choosing MCP joint arthroplasty included being younger and being female.

Gabriel, S. E., Campion, M. E., & O'Fallon, W. M. (1993). Patient preferences for non-steroidal anti-inflammatory drug related gastrointestinal complications and their prophylaxis. *Journal of Rheumatology, 20,* 358-361.
Refid: 122695
Main message:

- Among the adverse events associated with the use of non-steroidal anti-inflammatory drugs (NSAIDs), patients ranked surgery, hospitalization, and prophylaxis-induced diarrhea as the least desirable gastrointestinal (GI) complications.

Summary: This pilot study examined the preferences for avoiding adverse events that were associated with NSAID use. The results suggested that participants placed a high value on avoiding surgery, hospitalization, prophylaxis-induced diarrhea and uncomplicated ulcers. The avoidance of ulcer symptoms and the inconvenience of taking an additional medication for preventing GI complications four times daily appeared to be less important to these patients.

Martin, L. J. & Griffith, S. M. (2006). High disease activity scores predict the need for additional health services in patients over 60 with rheumatoid arthritis. *Musculoskeletal Care, 4,* 1-11.
Refid: 125245
Main message:

- A survey of people attending rheumatology outpatient clinics indicated that there was significant unmet demand for chiropody and footwear, education about RA, physiotherapy, occupational therapy and surgery.

Summary: A cross-sectional survey was conducted of 123 patients aged 60 years and over attending rheumatology outpatient clinics. Respondents were more likely to express a need for chiropody or footwear, physiotherapy or education about RA than for occupational therapy or surgery. Those respondents who had high disease activity scores and high anxiety scores showed a greater perceived need for additional health services.

Rheumatoid arthritis: Information – qualitative studies (N=6)

Marines Castillo, A. L., Salcido, G. P., Orozco, C., Osorio, C. M. (2000). Interes del paciente con artritis reumatoide por aprender acerca de la enfermedad. *Rev Mex Rheumat 15(5),* 131 – 6.
Refid: 320763
Main Message:

- People with RA are interested in knowing more about the disease, especially with respect to diet and exercise. The main source of information is newspapers.

Summary: In this study, a questionnaire was administered to 52 ambulatory patients (44 women and 8 men) with rheumatoid arthritis. The questionnaire involved four areas: general data, patients' interest for information concerning RA, popular concepts, and functional consequences of RA. A high interest was shown for knowing more about the disease, the main source of information was newspapers, and the most important items were diet and physical exercise. Medical information was received only by exception. Patients did not agree with the possibility of a cure, they did not believe the disease was contagious, and they did not believe that it occurred in children. Patients were instead convinced of a cause-effect relationship in which RA was caused by cold and temperature changes. They also believed that the disease can be controlled, believed in the concept of arthritis as a group of different diseases, and believed that

it was possible to lead an active life despite the disease. Having an interest in knowing more about the disease was clearly related to better functioning and a higher schooling degree.
**This article is in Spanish*

Ashe, B., Taylor, M., & Dubouloz, C. (2005). The process of change: listening to transformation in meaning perspectives of adults in arthritis health education groups. *Canadian Journal of Occupational Therapy, 72,* 280-288.
Refid: 110204
Main message:

- Education groups may facilitate the adoption of healthy behaviours in people with arthritis.

Summary: This study used qualitative interviews to explore patients' experiences in two different arthritis education groups to develop an understanding of meaningful group experiences. Ten participants with RA or other inflammatory arthritis were recruited. Individual and focus group interviews provided descriptions of experiences. The results showed that arthritis education group experiences led to improved perceptions of an ability to cope with the chronic disease. The idea that the patient's process of change can lead to healthy behaviours and desired health outcomes was also discussed.

Barlow, J. H., Cullen, L. A., & Rowe, I. F. (2002). Educational preferences, psychological well-being and self-efficacy among people with rheumatoid arthritis. *Patient Education & Counseling, 46,* 11-19.
Refid: 110302
Main messages:

- Education on the disease, treatments and emotional issues should be conducted on a one-to-one basis.
- Some patients with RA prefer group interventions for learning about self-management and exercise.

Summary: This mixed method design examined patients' preferences for interventions, as well as psychological well-being and self-efficacy. It examined addressing education, self-management and the consequences of RA. The results revealed that patients preferred education about the disease and its treatment, as well as emotional issues, to be delivered on a one-to-one basis by health professionals. Group interventions were the preferred format for self-management, exercise and relationship issues, whereas videos were thought to be useful for demonstrating the use of aids and showing how other families cope. The status of both physical and psychological health were correlated with arthritis self-efficacy.

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness, 4,* 167-182.
Refid: 110721
Main message:

- Chronically ill people can make adaptations to their lifestyle, but may have moments when they feel helpless, such as when symptoms are severe or following surgery.

Summary: The study used semi-structured qualitative interviews with patients with RA to describe the experience of onset and development of RA. The results highlighted the resources (cognitive and material) available to individuals, modes of explanation for pain and suffering, and factors that help explain variation in experience.

Dyck, I. (1992). Managing chronic illness: an immigrant woman's acquisition and use of health care knowledge. *American Journal of Occupational Therapy, 46,* 696-705.
Refid: 122122
Main message:

- For occupational therapy, careful consideration needs to be made about the social and economic circumstances of the client's life, especially for those who are disadvantaged.

Summary: This case study illustrated the role of family, community networks and workplace in the management of RA from the perspective of a Chinese-Canadian immigrant woman. Occupational therapy in a clinical setting was indentified as an important component in the management of her conditions. It showed how health care decisions were related to her life as a working-class immigrant woman.

Hughes, R. A., Carr, M. E., Huggett, A., & Thwaites, C. E. (2002). Review of the function of a telephone helpline in the treatment of outpatients with rheumatoid arthritis. *Annals of the Rheumatic Diseases, 61,* 341-345.
Refid: 123662
Main messages:

- Clinical advice and support can be provided by a rheumatology helpline set up as an adjunct to a standard outpatient service.
- Helpline services can improve the quality of care provided by an outpatient department and provide benefits to a social insurance health care system.

Summary: To assess patient satisfaction a postal questionnaire was sent to 87 patients who called the rheumatology helpline in a one-month period. The results indicated that 97% of the participants were satisfied with the response time and 100% were satisfied with the courtesy; 95% and 98% felt that their questions were answered directly and to their satisfaction, respectively. Had the helpline not been available, 60% of the patients would have made an appointment with their GP. The helpline produced a cost saving to the National Health Service, largely due to the GP consultations avoided.

Rheumatoid arthritis: Information – quantitative studies (N=18)

Berkanovic, E. & Hurwicz, M. L. (1995). Physician visits by rheumatoid arthritis patients: a prospective analysis. *Arthritis Care & Research, 8,* 73-79.
Refid: 120705
Main message:

- Variations in the types of physician visits by people with RA are related to both predisposing and enabling factors.

Summary: The purpose of this quantitative study was to examine patient-initiated physician visits, physician-requested visits and visits for disease flares by patients with RA. The results demonstrated that predisposing and enabling factors accounted for 50–67% of the explained variance in the three types of visits, while need accounted only for 33–50%. These results showed the need for further studies on the factors that influence both RA patients' decisions to seek care and physicians' decisions to request further visits.

Berkanovic, E., Hurwicz, M. L., & Batchlor, E. (1991). Rheumatoid arthritis and the use of medical services. *Arthritis Care & Research, 4*, 12-21.
Refid: 120707
Main message:

- The use of medical services by patients with RA is not a simple function of need.

Summary: This quantitative study analyzed the factors that are associated with the use of services among patients with RA. The data was derived from interviews with patients with RA. The results showed that predisposing variables such as age, sex, marital status, race and education, as well as enabling variables such as income and whether the patient with arthritis had health insurance, were related to service use.

Brekke, M., Hjortdahl, P., & Kvien, T. K. (2001). Involvement and satisfaction: A Norwegian study of health care among 1,024 patients with rheumatoid arthritis and 1,509 patients with chronic noninflammatory musculoskeletal pain. *Arthritis Care and Research, 45,* 8-15.
Refid: 120991
Main messages:

- A high level of education and contact with a rheumatologist are associated with a high level of health care involvement by the patient.
- High involvement and good mental health are associated with patient satisfaction with health care.

Summary: The purpose of this survey was to investigate involvement in and satisfaction with health care among patients with RA. The objective was to identify target areas for improvement. Being young, well educated, physically disabled, in good mental health and self-efficient correlated with a high level of involvement in health care. Satisfaction with health care was higher for patients who were female, had a low pain level, had good mental health and reported high self-efficacy.

Buckley, L. M., Vacek, P., & Cooper, S. M. (1990). Educational and psychosocial needs of patients with chronic disease: a survey of preferences of patients with rheumatoid arthritis. *Arthritis Care and Research, 3,* 5-10.
Refid: 121143
Main messages:

- Patients with RA have identified their most important issues as being good communication with the doctor, understanding their medication and dealing with their pain.
- Patients with RA are also concerned about the effects of arthritis on their quality of life.

Summary: This quantitative study surveyed patients with RA about the importance of psychosocial and educational issues, and asked them how they wished to receive help. The study examined individual variables, including sex, age, disease duration and disease severity, and their relationships to patients' choices. The issues rated most important by patients included communicating with the doctor; understanding their medication; dealing with their pain; and the effects of arthritis on their energy level, their participation at work and their future. Most patients preferred to seek help from their physicians, although many were willing to attend groups or see non-physician counsellors for individual counselling.

Cardiel, M. H. & Rojas-Serrano, J. (2002). Community-based study to estimate prevalence, burden of illness and help seeking behavior in rheumatic diseases in Mexico City. A COPCORD study. *Clinical & Experimental Rheumatology, 20,* 617-624.
Refid: 110792
Main message:

- A general practitioner treated 72% of patients with rheumatic diseases in Mexico City. Most patients responded well to the prescribed medication.

Summary: The purpose of this study was to estimate the prevalence of rheumatic diseases in a suburban community in Mexico City. The burden of illness and help-seeking behaviour of patients with rheumatic diseases were also examined. The results indicated that 419 participants (17%) had reported pain in the last seven days due to musculoskeletal disorders and 13% of the total sample had experienced some form of treatment.

Centers for Disease Control and Prevention (CDC) (2003). Adults who have never seen a health-care provider for chronic joint symptoms--United States, 2001. *MMWR - Morbidity & Mortality Weekly Report, 52,* 416-419.
Refid: 110828
Main message:

- One in five people with chronic joint symptoms are not seeking treatment for their joint symptoms.

Summary: The purpose of this CDC report was to estimate the prevalence of people with chronic joint symptoms who did not see a health care provider in 2001. The results indicated that one-fifth of the estimated population had never seen a health care provider for joint pain problems. Several factors contribute to these findings. For example, many patients have comorbidities that were more severe or life-threatening then their joint symptoms and so they might pay less attention to the latter. Also, some patients perceived arthritis as being part of the normal aging process and so felt that treatment was neither necessary nor beneficial.

Cho, K. J., Jang, S. H., Lee, S. K., & Doh, W. S. (1998). Utilization characteristics of health care service for rheumatoid arthritis patients in Korea. *Yonsei medical journal, 39,* 247-251.
Refid: 121456
Main messages:

- Patients with RA in Korea take longer to consult a medical doctor compared to patients with RA in the United States.
- One factor that contributes to this lag time includes the use of unconventional medicine (Chinese herbal medicine) or non-prescribed medicine after symptom onset.

Summary: The purpose of this study was to determine the factors responsible for delaying diagnosis and optimal management of RA in Korea. From the study sample of 98 patients, 51 patients consulted an orthopaedic surgeon, 19 patients consulted a Chinese herbal doctor and 16 patients consulted a pharmacist. In this study 59% of patients were diagnosed with RA by an orthopaedic surgeon, and 25% by a rheumatologist. Patients with RA in Korea lost twice as much time when consulting a medical doctor compared to patients with RA in the United States.

Garcia Popa-Lisseanu, M. G., Greisinger, A., Richardson, M., O'Malley, K. J., Janssen, N. M., Marcus, D. M., Tagore, J., & Suarez-Almazor, M. E. (2005). Determinants of treatment adherence in ethnically diverse, economically disadvantaged patients with rheumatic disease.

Journal of Rheumatology, 32, 913-919.
Refid: 122724
Main message:

- The main barriers to adherence to treatment are fear of side effects, financial problems, difficulty in navigating the public health system, and perceived treatment inefficacy.

Summary: This study aimed to examine the factors that affect adherence to medical recommendations among ethnically diverse and economically disadvantaged patients with RA and systemic lupus erythematosus (SLE) in Houston, Texas. The majority of participants reported experiencing difficulty in adhering to their treatment. Patients with SLE or RA reported similar barriers to adhering to treatment and to keeping appointments. The authors concluded that patients' perceptions of, and experiences with, the health system influenced their adherence to treatment.

Hewlett, S., Cockshott, Z., Byron, M., Kitchen, K., Tipler, S., Pope, D., & Hehir, M. (2005). Patients' perceptions of fatigue in rheumatoid arthritis: overwhelming, uncontrollable, ignored. *Arthritis & Rheumatism (Arthritis Care & Research), 53,* 697-702.
Refid: 123484
Main message:

- Fatigue associated with RA is significant, intrusive and overwhelming, and patients may struggle to manage it alone without adequate support.

Summary: This qualitative study interviewed 15 patients with RA about their experience in managing fatigue. Participants described two types of fatigue: severe weariness and dramatic overwhelming fatigue. RA fatigue was found to be extreme, unfounded and non-resolving. Participants described the physical, cognitive and emotional impact of feeling fatigued, and the effects on relationships and participation in social and family roles. They attributed fatigue to the inflammatory process, overuse of the joints and unrefreshing sleep. Participants used self-management strategies but with limited success. Most did not discuss fatigue with clinicians but when they did, they felt it was dismissed. Some participants held negative views on the management of fatigue due to limited success with their self-management strategies and limited guidance from health professionals, and a resulting perceived lack of control over their fatigue.

Hughes, R. A., Carr, M. E., Huggett, A., & Thwaites, C. E. (2002). Review of the function of a telephone helpline in the treatment of outpatients with rheumatoid arthritis. *Annals of the Rheumatic Diseases, 61,* 341-345.
Refid: 123662
Main messages:

- Clinical advice and support can be provided by a rheumatology helpline set up as an adjunct to a standard outpatient service.
- Helpline services can improve the quality of care provided by an outpatient department and provide benefits to a social insurance health care system.

Summary: To assess patient satisfaction a postal questionnaire was sent to 87 patients who called the rheumatology helpline in a one-month period. The results indicated that 97% of the participants were satisfied with the response time and 100% were satisfied with the courtesy; 95% and 98% felt that their questions were answered directly and to their satisfaction, respectively. Had the helpline not been available, 60% of the patients would have made an appointment with their GP. The helpline produced a cost saving to the National Health Service, largely due to the GP consultations avoided.

Jacobi, C. E., Triemstra, M., Rupp, I., Dinant, H. J., & van den Bos, G. A. (2001). Health care utilization among rheumatoid arthritis patients referred to a rheumatology center: unequal needs, unequal care? *Arthritis & Rheumatism, 45,* 324-330.
Refid: 123825
Main message:

- Most patients received the care they needed in the Netherlands; however, for older people with RA, there are problems with access to allied health care and psychosocial care.

Summary: A questionnaire survey was conducted among patients with RA in order to evaluate whether those in need of care actually received it. Health care use was assessed for medical care, allied health services, psychosocial counselling and home care. The results indicated that most patients received the care they needed. However, disease-related factors including age, sex and living situation were found to be predictive of the use of health services.

Kahn, K. L., MacLean, C. H., Liu, H., Rubenstein, L. Z., Wong, A. L., Harker, J. O., Chen, W. P., Fitzpatrick, D. M., Bulpitt, K. J., Traina, S. B., Mittman, B. S., Hahn, B. H., & Paulus, H. E. (2007). The complexity of care for patients with rheumatoid arthritis: metrics for better understanding chronic disease care. *Medical care, 45,* 55-65.
Refid: 123996
Main message:

- While patients with RA have frequent encounters with multiple providers, many also stop seeing a health professional possibly because of a lack of health care providers or because they only seek health professionals when they are needed urgently.

Summary: This prospective cohort study of 568 RA patients used observational data from telephone interviews to study health status, comorbidity, use of disease-modifying anti-rheumatic drugs, visits to care providers, provider types, encounter settings and the discontinuity between patients and providers. The results indicated that during a 12-month period patients on average saw three to four health care providers in the outpatient setting. Over the course of 24 months, 29% of patients changed their primary care provider and 15% changed their rheumatologist.

Kjeken, I., Dagfinrud, H., Mowinckel, P., Uhlig, T., Kvien, T. K., & Finset, A. (2006). Rheumatology care: Involvement in medical decisions, received information, satisfaction with care, and unmet health care needs in patients with rheumatoid arthritis and ankylosing spondylitis. *Arthritis & Rheumatism, 55,* 394-401.
Refid: 124337
Main message:

- There is a need for a more flexible and patient-centred care model in which patients with RA or ankylosing spondylitis can decide which services they need and how they should be delivered.

Summary: Questionnaires were completed by 1,193 patients with RA and ankylosing spondylitis. The majority of patients reported medium to high levels of information received about RA, involvement in medical decisions and satisfaction with care. High involvement in medical decisions was associated with high levels of perceived information and satisfaction, as well as with lower age and a good health status. Patient satisfaction, a high level of received information, age and 12+ years of formal education were significant predictors to current involvement. Nearly one-third of the respondents reported a variety of unmet health care needs, and this report was associated with poor health.

Martin, L. J. & Griffith, S. M. (2006). High disease activity scores predict the need for additional health services in patients over 60 with rheumatoid arthritis. *Musculoskeletal Care, 4,* 1-11.
Refid: 125245
Main message:

- A survey of people attending rheumatology outpatient clinics indicated that there was significant unmet demand for chiropody and footwear, education about RA, physiotherapy, occupational therapy and surgery.

Summary: A cross-sectional survey was conducted of 123 patients aged 60 years and over attending rheumatology outpatient clinics. Respondents were more likely to express a need for chiropody or footwear, physiotherapy or education about RA than for occupational therapy or surgery. Those respondents who had high disease activity scores and high anxiety scores showed a greater perceived need for additional health services.

McCabe, C., McDowell, J., Cushnaghan, J., Butts, S., Hewlett, S., Stafford, S., O'Hea, J., & Breslin, A. (2000). Rheumatology telephone helplines: an activity analysis. South and West of England Rheumatology Consortium. *Rheumatology, 39,* 1390-1395.
Refid: 125332
Main message:

- Rheumatology helpline services in the UK lacked uniformity in the delivery of care and accessibility to relevant patient groups. These differences could result in patient dissatisfaction and confusion, and the creation of national guidelines is recommended.

Summary: Information was collected on the first 100 calls received by six rheumatology helplines in the south and west of England. Background information was gathered on the management, availability, setting and purpose of each helpline. The results indicated that patients with RA were the major users and no significant differences were found in the outcome of their calls between centres, although wide variations were found in the operation of the helplines, the populations they serve and the services they offer.

Ramos-Remus, C., Watters, C. A., Dyke, L., Suarez-Almazor, M. E., & Russell, A. S. (1999). Assessment of health locus of control in the use of nonconventional remedies by patients with rheumatic diseases. *Journal of Rheumatology, 26,* 2468-2474.
Refid: 126582
Main message:

- Over half of respondents used nonconventional remedies (NCR) for their RA symptoms, but fewer than 2 in 10 told their rheumatologist about them. NCR users tend to be younger, more disabled and in the middle income class.

Summary: A cross-sectional survey and qualitative interview of 200 patients with rheumatic diseases in Edmonton, Canada, was conducted to evaluate the prevalence of use, and patients' beliefs, perceptions and expectations in relation to NCR. The results showed that 60% of the study patients had used NCR in the previous 12 months, 47% had received at least one NCR before the first rheumatology consultation and an additional 8% initiated NCR after their initial contact with a rheumatologist. Only 18% of the patients using NCR notified their rheumatologist about their use. Patients who used NCR in the preceding 12 months were younger, slightly more disabled and in the middle income class.

Riemsma, R. P., Klein, G., Taal, E., Rasker, J. J., Houtman, P. M., van Paassen, H. C., & Wiegman, O. (1998). The supply of and demand for informal and professional care for patients with rheumatoid arthritis. *Scandinavian journal of rheumatology, 27,* 7-15.
Refid: 126708
Main message:

- The amount of help received by patients with RA is related to the physical condition of the patient, marital status of the patient and sex of the caregiver.

Summary: A survey of patients with RA and their caregivers found that in general patients received the help they needed. Most help given at home was provided by informal caregivers such as friends and family of the patient. The amount of help received from informal caregivers is largely explained by the patient's physical condition and marital status, the sex of the caregiver, the patient's expectations of their ability to cope with RA and the age of the patient. The amount of help received from health professionals is related primarily to the marital status and physical condition of the patient.

Saag, K. G., Doebbeling, B. N., Rohrer, J. E., Kolluri, S., Mitchell, T. A., & Wallace, R. B. (1998). Arthritis health service utilization among the elderly: The role of urban-rural residence and other utilization factors. *Arthritis Care and Research, 11,* 177-185.
Refid: 126901
Main message:

- There is a consistent association of need factors, joint swelling and a diagnosis of RA with physician utilization. Urban/rural status does not appear to independently influence the use of health care providers for arthritis care.

Summary: A population-based telephone interview survey was conducted on a random sample of 488 adults aged 65 or older with self-reported arthritis, with about half the sample from urban communities and half from rural communities. The results indicated that urban respondents were more commonly reported as having received a diagnosis of osteoarthritis from their physicians but being less likely to report RA. A greater proportion of urban versus rural respondents had seen a physician for their arthritis and had seen an orthopaedist or general internist more often. Some factors were significantly associated with prior rheumatologist use; for example, diagnosis of RA, being younger, living with someone, having a higher income and being further from an arthritis care provider.

Osteoarthritis: Diagnosis – qualitative studies (N=2)

Powanda,M. C. (2003). The impatient patient: A personal view of osteoarthritis. *Inflammopharmacology, 11(4-6),* 317 – 322.
Refid: 134984
Main Message:

- A qualitative autobiographical account of dealing with osteoarthritis, and a call for more research into the biomechanics of this disease.

Summary: A qualitative account of one man's experience with osteoarthritis (OA), the process of obtaining a diagnosis and dealing with the symptoms. He talks about exercise, surgery medications, and the impact of pain and debilitation on his personal mental and emotional state as well as those of his friends and family. He implores for more research in the field of biomechanics which may lead to more effective painkillers and OA medications.

Baumann, M., Euller-Ziegler, L., & Guillemin, F. (2007). Evaluation of the expectations osteoarthritis patients have concerning healthcare, and their implications for practitioners. *Clinical & Experimental Rheumatology, 25,* 404-409.
Refid: 130418
Main message:

- Understanding patients' expectations is essential for improving the therapeutic process and patient care.

Summary: In this qualitative study, patients with OA were recruited and focus groups were conducted. The focus groups looked at patients' expectations of information about osteoarthritis; the attitudes of practitioners and communication between health professionals; and the support available from doctors, their family circle and society. The results suggested the patient-practitioner relationship could be improved if greater trust and better communication skills were developed, and if the practitioner were able to express sympathy. It was also suggested that general practitioners should act as mediators and facilitators to improve recognition and understanding of osteoarthritis by employers and public decision-makers.

Osteoarthritis: Diagnosis – quantitative studies (N=1)

Saag, K. G., Doebbeling, B. N., Rohrer, J. E., Kolluri, S., Mitchell, T. A., & Wallace, R. B. (1998). Arthritis health service utilization among the elderly: The role of urban-rural residence and other utilization factors. *Arthritis Care and Research, 11,* 177-185.
Refid: 126901
Main message:

- There is a consistent association of need factors, joint swelling and a diagnosis of RA with physician utilization. Urban/rural status does not appear to independently influence the use of health care providers for arthritis care.

Summary: A population-based telephone interview survey was conducted on a random sample of 488 adults aged 65 or older with self-reported arthritis, with about half the sample from urban communities and half from rural communities. The results indicated that urban respondents were more commonly reported as having received a diagnosis of osteoarthritis from their physicians but being less likely to report RA. A greater proportion of urban versus rural respondents had seen a physician for their arthritis and had seen an orthopaedist or general internist more often. Some factors were significantly associated with prior rheumatologist use; for example, diagnosis of RA, being younger, living with someone, having a higher income and being further from an arthritis care provider.

Osteoarthritis: Medication – qualitative studies (N=5)

Baumann, M., Euller-Ziegler, L., & Guillemin, F. (2007). Evaluation of the expectations osteoarthritis patients have concerning healthcare, and their implications for practitioners. *Clinical & Experimental Rheumatology, 25,* 404-409.
Refid: 130418

Main message:

- Understanding patients' expectations is essential for improving the therapeutic process and patient care.

Summary: In this qualitative study, osteoarthritis patients were recruited and focus groups were conducted. The focus groups looked at patients' expectations of information about osteoarthritis; the attitudes of practitioners and communication between health professionals; and the support available from doctors, their family circle and society. The results suggested the patient-practitioner relationship could be improved if greater trust and better communication skills were developed, and if the practitioner were able to express sympathy. It was also suggested that general practitioners should act as mediators and facilitators to improve recognition and understanding of osteoarthritis by employers and public decision-makers.

Bower, K. N., Frail, D., Twohig, P. L., & Putnam, W. (2006). What influences seniors' choice of medications for osteoarthritis? Qualitative inquiry. *Canadian Family Physician, 52,* 342-343.
Refid: 130723

Main message:

- Access to free sample medication, physicians' recommendations and fear of side effects influenced medication choices for seniors.

Summary: The purpose of this qualitative study was to determine what influences seniors' choices of medication for osteoarthritis. Four themes emerged from interviews conducted about medication choices: the role of family physicians, the effect of fear, the reasons for discontinuing medication use and views on other information sources. This study also discussed the perception that seniors claimed not to be influenced by consumer advertising or the fact that some arthritis medications are more expensive then others.

Mikhail, S. S., Zwar, N. A., Vagholkar, S., Dennis, S. M., & Day, R. O. (2007). Non-steroidal anti-inflammatory drugs in general practice: a decision-making dilemma. *Medical Journal of Australia, 187,* 160-163.
Refid: 134294

Main message:

- There is a need to provide clear, unbiased information about non-steroidal anti-inflammatory drugs (NSAIDs) to help both GPs and patients negotiate the decision-making process.

Summary: Five focus groups (three for GPs and two for patients with OA) were conducted in southwestern Sydney, Australia, to examine decision-making about NSAIDs and to explore issues concerning the use of NSAIDs from both prescriber and consumer perspectives. The results showed that GPs are cautious when prescribing NSAIDs because of medicolegal concerns and uncertainty about their safety ; they were skeptical about information provided by the pharmaceutical industry because they found it confusing. Time was identified as a major barrier to adequate discussion with patients, and explaining the risk to patients in a meaningful way was perceived as a challenge. Patients wanted information and sought it from a range of sources, most commonly pharmacists and GPs. Most patients made active decisions about using or not using NSAIDs, with some favouring physical function over safety.

Powanda,M. C. (2003). The impatient patient: A personal view of osteoarthritis. *Inflammopharmacology, 11(4-6),* 317 – 322.

Refid: 134984
Main Message:

- A qualitative autobiographical account of dealing with osteoarthritis, and a call for more research into the biomechanics of this disease.

Summary: A qualitative account of one man's experience with osteoarthritis (OA), the process of obtaining a diagnosis and dealing with the symptoms. He talks about exercise, surgery medications, and the impact of pain and debilitation on his personal mental and emotional state as well as those of his friends and family. He implores for more research in the field of biomechanics which may lead to more effective painkillers and OA medications.

Tallon,D., Chard,J., Dieppe,P. (2000). Exploring the priorities of patients with osteoarthritis of the knee, *Arthritis Care & Research, 13(5)*, 312 – 319.
Refid: 136106
Main Message:

- The lack of a patient-centered approach to care leads professionals to ignore key symptoms and issues for individuals, and to a preoccupation with pharmaceutical interventions, rather than the treatment options that their patients prefer.

Summary: A questionnaire was designed to explore the perceived importance of symptoms, treatment preferences, and research priorities of people with osteoarthritis (OA) of the knee, and was distributed to 112 people with knee OA. Pain, disability, and instability in the joint were the most important symptoms, and anxiety about knee OA caused distress to many people. Oral drugs (90%), physical therapy (62%), and aids and adaptations (56%) were the most commonly used treatments. Surgery, oral drugs, and intra-articular injections were perceived as the most efficacious interventions. Patients' highest priorities for research were surgery and educational interventions, despite the fact that few had had surgery and education was not perceived as very effective.

Osteoarthritis: Medication – quantitative studies (N=6)

Cardiel, M. H. & Rojas-Serrano, J. (2002). Community-based study to estimate prevalence, burden of illness and help seeking behavior in rheumatic diseases in Mexico City. A COPCORD study. *Clinical & Experimental Rheumatology, 20,* 617-624.
Refid: 110792
Main message:

- A general practitioner treated 72% of patients with rheumatic diseases in Mexico City. Most patients responded well to the prescribed medication.

Summary: The purpose of this study was to estimate the prevalence of rheumatic diseases in a suburban community in Mexico City. The burden of illness and help-seeking behaviour of patients with rheumatic diseases were also examined. The results indicated that 419 participants (17%) had reported pain in the last seven days due to musculoskeletal disorders and 13% of the total sample had experienced some form of treatment.

Cronan, T. A., Shaw, W. S., Gallagher, R. A., & Weisman, M. (1995). Predicting health care use among older osteoarthritis patients in an HMO. *Arthritis Care and Research, 8,* 66-72.
Refid: 131330
Main message:

- The best predictor of health care use among older patients with OA in a health maintenance organization (HMO) is their prior use of health services.

Summary: This study examined factors that predicted health care use among older members of an HMO who had osteoarthritis. The frequency of physician visits, phone calls, emergency room visits and inpatient stays were recorded. Factors such as age, health and psychological status were examined. The results showed that being older and more physically impaired, and having lower well-being scores were predictors of health care use.

Heijmans,M., Foets,M., Rijken,M., Schreurs,K., De Ridder,D., Bensing,J. (2001). Stress in chronic disease: Do the perceptions of patients and their general practitioners match? *British Journal of Health Psychology, 6(3),* 229 – 242.
Refid: 132566
Main Message:

- There is incongruence between patients' and general practitioners' (GP) ideas about the stressors that accompany chronic diseases, which is associated with a worse health status of the patient and an increase in healthcare use.

Summary: Questionnaire interviews were conducted with 580 patients with a diagnosis of diabetes or osteoarthritis and their GPs about the stressors accompanying a patient's illness, and information was obtained from each patient on health status and use of health care. Results show that patient and GP diverge in the way they think about chronic illness; this incongruence was larger in the case of osteoarthritis. Incongruence between patient and GP was associated with a worse health status of the patient and an increase in health-care use, although the pattern of correlation differed by type of disease. It is important that providers recognize the personal impact that a chronic disease has on the patient's life instead of just focusing on the medical aspects of disease.

Ibrahim,S. A., Siminoff,L. A., Burant,C. J., Kwoh,C. K. (2001). Variation in perceptions of treatment and self-care practices in elderly with osteoarthritis: a comparison between African American and white patients., *Arthritis & Rheumatism (Arthritis Care & Research), 45(4),* 340 – 345.
Refid: 132807
Main Message:

- African American and Caucasian patients with osteoarthritis of the knee or hip differ with respect to their perceptions of traditional and complementary treatments for arthritis and their self-care practices.

Summary: This observational, cross-sectional study used structured questionnaires to compare the perceptions of the efficacy of traditional and complementary treatments and their self-care practices between elderly African American and Caucasian patients. The study sample consisted of 593 patients (44% African American and 56% Caucasian) from Ohio; the two groups were comparable with respect to age, disease severity or functional status, and comorbidities. African Americans were more likely to report lower educational level and household income than Caucasians. African Americans were also more likely to perceive various traditional and complementary care modalities as efficacious. However, they were less likely than Caucasians to perceive joint replacement therapy as efficacious, and more likely to rely on self-care measures for their arthritis.

Liu,Y., Doucette,W. R., Farris,K. B. (2007). Perceived difficulty and self-efficacy in the factor structure of perceived behavioral control to seek drug information from physicians and pharmacists. *Research in Social & Administrative Pharmacy: RSAP, 3(2),* 145 – 159.
Refid: 133742
Main Message:

- The concept of perceived behavioral control (PBC) in the Theory of Planned Behavior can be broken down into two dimensions: perceived difficulty and self-efficacy. Controllability impacts whether perceived difficulty and self-efficacy overlap or diverge, with higher controllability associated with distinct dimensions.

Summary: In the Theory of Planned Behavior, perceived behavioral control (PBC) has been directly measured in 3 different ways, i.e. perceived difficulty, self-efficacy, and controllability. This study explored the relationship of perceived difficulty and self-efficacy in the factor structure of PBC, and examined the impact of controllability on this relationship. The study context was osteoarthritis patients' drug information seeking from physicians and pharmacists for advertised anti-arthritic prescription medications. One thousand patients were randomly selected from 3000 nationwide osteoarthritis patients. A self-administered survey collected perceived difficulty (3 items), self-efficacy (3 items), and controllability (2 items) of drug information seeking from physicians and pharmacists. The response rate was 61.9%. Perceived difficulty and self-efficacy may represent 2 dimensions of an overall concept. Controllability impacts whether perceived difficulty and self-efficacy overlap or diverge, with higher controllability associated with distinct dimensions.

Liu, Y., Doucette, W. R., Farris, K. B., & Nayakankuppam, D. (2005). Drug information-seeking intention and behavior after exposure to direct-to-consumer advertisement of prescription drugs. *Research In Social & Administrative Pharmacy: RSAP, 1,* 251-269.
Refid: 113049
Main messages:

- Direct-to-consumer advertisements (DTCA) may prompt drug information-seeking, but do not influence decisions about treatment choices.
- Interventions could address patients' attitudes toward behavior, the influence of their important others and their role as information seeker.

Summary: The purpose of the survey was to identify predictors of patients' intentions and behaviours to seek drug information from physicians, pharmacists and the Internet after exposure to direct-to-consumer marketing using theories of planned behavior (TPB) and self-efficacy. The questionnaire was sent to 1,000 patients. Of those, 454 had prior exposure to DTCA. The results showed that TPB accounted for 40-50% of the variance for patients' intentions to seek drug information, and 19-38% of the variance for the action of drug information-seeking.

Osteoarthritis: Allied health – qualitative studies (N=3)

Baumann, M., Euller-Ziegler, L., & Guillemin, F. (2007). Evaluation of the expectations osteoarthritis patients have concerning healthcare, and their implications for practitioners. *Clinical & Experimental Rheumatology, 25,* 404-409.
Refid: 130418
Main message:

- Understanding patients' expectations is essential for improving the therapeutic process and patient care.

Summary: In this qualitative study, osteoarthritis patients were recruited and focus groups were conducted. The focus groups looked at patients' expectations of information about osteoarthritis; the attitudes of practitioners and communication between health professionals; and the support available from doctors, their family circle and society. The results suggested the patient-practitioner relationship could be improved if greater trust and better communication skills were developed, and if the practitioner were able to express sympathy. It was also suggested that general practitioners should act as mediators and facilitators to improve recognition and understanding of osteoarthritis by employers and public decision-makers.

Powanda,M. C. (2003). The impatient patient: A personal view of osteoarthritis. *Inflammopharmacology*, *11(4-6),* 317 – 322.
Refid: 134984
Main Message:

- A qualitative autobiographical account of dealing with osteoarthritis, and a call for more research into the biomechanics of this disease.

Summary: A qualitative account of one man's experience with osteoarthritis (OA), the process of obtaining a diagnosis and dealing with the symptoms. He talks about exercise, surgery medications, and the impact of pain and debilitation on his personal mental and emotional state as well as those of his friends and family. He implores for more research in the field of biomechanics which may lead to more effective painkillers and OA medications.

Tallon,D., Chard,J., Dieppe,P. (2000). Exploring the priorities of patients with osteoarthritis of the knee, *Arthritis Care & Research, 13(5),* 312 – 319.
Refid: 136106
Main Message:

- The lack of a patient-centered approach to care leads professionals to ignore key symptoms and issues for individuals, and to a preoccupation with pharmaceutical interventions, rather than the treatment options that their patients prefer.

Summary: A questionnaire was designed to explore the perceived importance of symptoms, treatment preferences, and research priorities of people with osteoarthritis (OA) of the knee, and was distributed to 112 people with knee OA. Pain, disability, and instability in the joint were the most important symptoms, and anxiety about knee OA caused distress to many people. Oral drugs (90%), physical therapy (62%), and aids and adaptations (56%) were the most commonly used treatments. Surgery, oral drugs, and intra-articular injections were perceived as the most efficacious interventions. Patients' highest priorities for research were surgery and educational interventions, despite the fact that few had had surgery and education was not perceived as very effective.

Osteoarthritis: Allied health – quantitative studies (N=7)

Cardiel, M. H. & Rojas-Serrano, J. (2002). Community-based study to estimate prevalence, burden of illness and help seeking behavior in rheumatic diseases in Mexico City. A COPCORD study. *Clinical & Experimental Rheumatology, 20,* 617-624.
Refid: 110792

Main message:

- A general practitioner treated 72% of patients with rheumatic diseases in Mexico City. Most patients responded well to the prescribed medication.

Summary: The purpose of this study was to estimate the prevalence of rheumatic diseases in a suburban community in Mexico City. The burden of illness and help-seeking behaviour of patients with rheumatic diseases were also examined. The results indicated that 419 participants (17%) had reported pain in the last seven days due to musculoskeletal disorders and 13% of the total sample had experienced some form of treatment.

Cronan, T. A., Shaw, W. S., Gallagher, R. A., & Weisman, M. (1995). Predicting health care use among older osteoarthritis patients in an HMO. *Arthritis Care and Research, 8,* 66-72.
Refid: 131330

Main message:

- The best predictor of health care use among older patients with OA in a health maintenance organization (HMO) is their prior use of health services.

Summary: This study examined factors that predicted health care use among older members of an HMO who had osteoarthritis. The frequency of physician visits, phone calls, emergency room visits and inpatient stays were recorded. Factors such as age, health and psychological status were examined. The results showed that being older and more physically impaired, and having lower well-being scores were predictors of health care use.

Heijmans,M., Foets,M., Rijken,M., Schreurs,K., De Ridder,D., Bensing,J. (2001). Stress in chronic disease: Do the perceptions of patients and their general practitioners match? *British Journal of Health Psychology, 6(3),* 229 – 242.
Refid: 132566

Main Message:

- There is incongruence between patients' and general practitioners' (GP) ideas about the stressors that accompany chronic diseases, which is associated with a worse health status of the patient and an increase in healthcare use.

Summary: Questionnaire interviews were conducted with 580 patients with a diagnosis of diabetes or osteoarthritis and their GPs about the stressors accompanying a patient's illness, and information was obtained from each patient on health status and use of health care. Results show that patient and GP diverge in the way they think about chronic illness; this incongruence was larger in the case of osteoarthritis. Incongruence between patient and GP was associated with a worse health status of the patient and an increase in health-care use, although the pattern of correlation differed by type of disease. It is important that providers recognize the personal impact that a chronic disease has on the patient's life instead of just focusing on the medical aspects of disease.

Hsieh,J. B., Dominick,K. L. (2003). Use of non-pharmacological therapies among patients with osteoarthritis. *Aging-Clinical & Experimental Research, 15(5),* 419 – 425.
Refid: 132730

Main Message:

- In a sample of 205 veterans with OA there was relatively low use of exercise, PT, and dietary/herbal supplements. Patients' perceptions of treatment helpfulness and physician recommendations strongly predicted use. Interventions should aim to educate both patients and physicians about these therapies.

Summary: A survey regarding OA symptoms and treatments was administered to 205 veterans in order to examine the prevalence of self-reported use of common non-pharmacological therapies as well as patient- and physician-related predictors of use. 94 subjects (46%) reported current use of exercise, 23 (11%) reported using PT, and 24 (12%) dietary/herbal supplements. Patient demographic and clinical characteristics were generally poor predictors of use of non-pharmacological therapy. Females were more likely to report exercising than males, and patients with greater disease severity were more likely to report current use of PT. Patients' perceived helpfulness of each therapy significantly predicted use ($p<0.05$). Physician demographic characteristics were not strong predictors of patients' use of therapy, but physician recommendation for exercise and PT predicted patients' use ($p<0.05$).

Ibrahim,S. A., Siminoff,L. A., Burant,C. J., Kwoh,C. K. (2001). Variation in perceptions of treatment and self-care practices in elderly with osteoarthritis: a comparison between African American and white patients., *Arthritis & Rheumatism (Arthritis Care & Research), 45(4),* 340 – 345.
Refid: 132807
Main Message:

- African American and Caucasian patients with osteoarthritis of the knee or hip differ with respect to their perceptions of traditional and complementary treatments for arthritis and their self-care practices.

Summary: This observational, cross-sectional study used structured questionnaires to compare the perceptions of the efficacy of traditional and complementary treatments and their self-care practices between elderly African American and Caucasian patients. The study sample consisted of 593 patients (44% African American and 56% Caucasian) from Ohio; the two groups were comparable with respect to age, disease severity or functional status, and comorbidities. African Americans were more likely to report lower educational level and household income than Caucasians. African Americans were also more likely to perceive various traditional and complementary care modalities as efficacious. However, they were less likely than Caucasians to perceive joint replacement therapy as efficacious, and more likely to rely on self-care measures for their arthritis.

Saag, K. G., Doebbeling, B. N., Rohrer, J. E., Kolluri, S., Mitchell, T. A., & Wallace, R. B. (1998). Arthritis health service utilization among the elderly: The role of urban-rural residence and other utilization factors. *Arthritis Care and Research, 11,* 177-185.
Refid: 126901
Main message:

- There is a consistent association of need factors, joint swelling and a diagnosis of RA with physician utilization. Urban/rural status does not appear to independently influence the use of health care providers for arthritis care.

Summary: A population-based telephone interview survey was conducted on a random sample of 488 adults aged 65 or older with self-reported arthritis, with about half the sample from urban communities and half from rural communities. The results indicated that urban respondents were more commonly reported as having received a diagnosis of osteoarthritis from their physicians but being less likely to report RA. A greater proportion of urban versus rural respondents had seen a physician for their arthritis and had seen an orthopaedist or general internist more often. Some factors were significantly associated with prior rheumatologist use; for example, diagnosis of RA, being younger, living with someone, having a higher income and being further from an arthritis care provider.

Swirtun, L. R., Eriksson, K., & Renstrom, P. (2006). Who chooses anterior cruciate ligament reconstruction and why? A 2-year prospective study. *Scandinavian journal of medicine & science in sports, 16,* 441-446.
Refid: 136068
Main message:

- The reason for most patients choosing to undergo early reconstruction (ER) was the assumption of future problems with the injured knee, rather than their current experience of with the knee function. However, the choice of undergoing late reconstruction (LR) appeared to be linked to the person's experience of the knee function.

Summary: Thirty-six patients with knee OA who chose anterior cruciate ligament reconstructive surgery were questioned about the reasons behind their decision. A high pre-injury activity level was associated with the choice of ACL reconstruction, but the choice of treatment was not associated with age, sex or the outcome variables measured. The 75% of the subjects who chose ER based their decision on assumptions of future problems rather than their knee function, and the 88% who chose reconstructive surgery later based their decision on their experience of knee function.

Osteoarthritis: CAT – qualitative studies (N=1)

Rao, J. K., Arick, R., Mihaliak, K., & Weinberger, M. (1998). Using focus groups to understand arthritis patients' perceptions about unconventional therapy. *Arthritis Care & Research, 11,* 253-260.
Refid: 114120
Main message:

- Patients with OA and RA would use unconventional therapies (UT) to relieve pain. The source of information about UT is important, but cost is not.

Summary: Focus groups of randomly selected patients with arthritis, four groups of RA patients and one group of OA patients, each containing 20–30 people, were conducted to discuss their beliefs about arthritis and UT. All the participants believed arthritis to be incurable by conventional regimens or UT. Over half the participants had used UT to relieve pain despite the cost. Patients trusted information about UT from family, friends and others with arthritis, but not information from supermarket tabloids or television commercials. Most discussed UT use with their physician, primarily to prevent interactions with prescribed treatments. Physicians' reactions ranged from ridicule to giving permission to continue using UT.

Osteoarthritis: CAT – quantitative studies (N=6)

Cardiel, M. H. & Rojas-Serrano, J. (2002). Community-based study to estimate prevalence, burden of illness and help seeking behavior in rheumatic diseases in Mexico City. A COPCORD study. *Clinical & Experimental Rheumatology, 20,* 617-624.

Refid: 110792

Main message:

- A general practitioner treated 72% of patients with rheumatic diseases in Mexico City. Most patients responded well to the prescribed medication.

Summary: The purpose of this study was to estimate the prevalence of rheumatic diseases in a suburban community in Mexico City. The burden of illness and help-seeking behaviour of patients with rheumatic diseases were also examined. The results indicated that 419 participants (17%) had reported pain in the last seven days due to musculoskeletal disorders and 13% of the total sample had experienced some form of treatment.

Cronan, T. A., Kaplan, R. M., & Kozin, F. (1993). Factors affecting unprescribed remedy use among people with self-reported arthritis. *Arthritis Care and Research, 6,* 149-155.

Refid: 121717

Main message:

- Unprescribed remedies are frequently used by patients with arthritis, and are rated by patients as effective as prescribed remedies.

Summary: The purpose of this study was to determine the frequency and consequences of use of unprescribed remedies by people with self-reported osteoarthritis, and to identify factors that predict such use. Of the 382 participants with self-reported musculoskeletal disorders involved, the results showed that 84% had used at least one unprescribed remedy during the past six months. People with self-reported RA used more such remedies than those with self-reported osteoarthritis, and those with a greater degree of disability used more unprescribed remedies than those who were less affected.

Heijmans,M., Foets,M., Rijken,M., Schreurs,K., De Ridder,D., Bensing,J. (2001). Stress in chronic disease: Do the perceptions of patients and their general practitioners match? *British Journal of Health Psychology, 6(3),* 229 – 242.

Refid: 132566

Main Message:

- There is incongruence between patients' and general practitioners' (GP) ideas about the stressors that accompany chronic diseases, which is associated with a worse health status of the patient and an increase in healthcare use.

Summary: Questionnaire interviews were conducted with 580 patients with a diagnosis of diabetes or osteoarthritis and their GPs about the stressors accompanying a patient's illness, and information was obtained from each patient on health status and use of health care. Results show that patient and GP diverge in the way they think about chronic illness; this incongruence was larger in the case of osteoarthritis. Incongruence between patient and GP was associated with a worse health status of the patient and an increase in health-care use, although the pattern of correlation differed by type of disease. It is important that providers recognize the personal impact that a chronic disease has on the patient's life instead of just focusing on the medical aspects of disease.

Hsieh,J. B., Dominick,K. L. (2003). Use of non-pharmacological therapies among patients with osteoarthritis. *Aging-Clinical & Experimental Research, 15(5),* 419 – 425.

Refid: 132730

Main Message:

- In a sample of 205 veterans with OA there was relatively low use of exercise, PT, and dietary/herbal supplements. Patients' perceptions of treatment helpfulness and physician recommendations strongly predicted use. Interventions should aim to educate both patients and physicians about these therapies.

Summary: A survey regarding OA symptoms and treatments was administered to 205 veterans in order to examine the prevalence of self-reported use of common non-pharmacological therapies as well as patient- and physician-related predictors of use. 94 subjects (46%) reported current use of exercise, 23 (11%) reported using PT, and 24 (12%) dietary/herbal supplements. Patient demographic and clinical characteristics were generally poor predictors of use of non-pharmacological therapy. Females were more likely to report exercising than males, and patients with greater disease severity were more likely to report current use of PT. Patients' perceived helpfulness of each therapy significantly predicted use ($p<0.05$). Physician demographic characteristics were not strong predictors of patients' use of therapy, but physician recommendation for exercise and PT predicted patients' use ($p<0.05$).

Ibrahim,S. A., Siminoff,L. A., Burant,C. J., Kwoh,C. K. (2001). Variation in perceptions of treatment and self-care practices in elderly with osteoarthritis: a comparison between African American and white patients., *Arthritis & Rheumatism (Arthritis Care & Research), 45(4),* 340 – 345.
Refid: 132807
Main Message:

- African American and Caucasian patients with osteoarthritis of the knee or hip differ with respect to their perceptions of traditional and complementary treatments for arthritis and their self-care practices.

Summary: This observational, cross-sectional study used structured questionnaires to compare the perceptions of the efficacy of traditional and complementary treatments and their self-care practices between elderly African American and Caucasian patients. The study sample consisted of 593 patients (44% African American and 56% Caucasian) from Ohio; the two groups were comparable with respect to age, disease severity or functional status, and comorbidities. African Americans were more likely to report lower educational level and household income than Caucasians. African Americans were also more likely to perceive various traditional and complementary care modalities as efficacious. However, they were less likely than Caucasians to perceive joint replacement therapy as efficacious, and more likely to rely on self-care measures for their arthritis.

Testerman, J. K., Morton, K. R., Mason, R. A., & Ronan, A. M. (2004). Patient Motivations for Using Complementary and Alternative Medicine. *Complementary Health Practice Review, 9,* 81-92.
Refid: 115002
Main message:

- Patients use CAM because they feel that the treatment is consistent with their worldview, and because conventional care is not relieving their symptoms.

Summary: This study surveyed 230 patients with osteoarthritis and/or depression plus 60 patients without these conditions in an outpatient setting about their health beliefs and use of complementary and alternative therapies. The results showed that holistic health beliefs, higher spirituality scores and lower health functional status were predictive of more CAM use whereas personal control over health and satisfaction with physicians were not. Depressed or arthritic patients were more likely than patients without those conditions to use CAM.

Osteoarthritis: Surgery – qualitative studies (N=11)

Ballantyne, P. J., Gignac, M. A., & Hawker, G. A. (2007). A patient-centered perspective on surgery avoidance for hip or knee arthritis: lessons for the future. *Arthritis & Rheumatism, 57,* 27-34.
Refid: 130362
Main messages:

- Individuals' perceptions of treatment options for arthritis are influenced by their previous medical encounters.
- Patients may benefit from additional counseling on effective medical and surgical treatments.

Summary: This qualitative study aimed to understand the discrepancy between patient preference and a need for total joint arthroplasty (TJA). Participant interviews were used to assess the coping strategies of patients with advanced osteoarthritis who had expressed a preference to avoid TJA. The results showed that participants frequently normalized the functional decline as being due to age and rejected arthritis-related medical treatments. Previous negative encounters in medical and surgical care, combined with the perceptions reinforced by physicians and others, deterred patients from seeking arthritis-related help in the health care system.

Callaghan, J. J. (1996). A 76- year-old woman considering total hip replacement. *JAMA, 276,* 486-491.
Refid: 130945
Main message:

- The patient is a key decision-maker about total hip replacement surgery. As an educator, the surgeon should provide all the relevant information to help the patient make an informed decision.

Summary: This qualitative study is a narrative of an elderly patient who is considering total hip replacement surgery. The patient did not think that her pain was severe enough to justify hip surgery, and therefore did not make a decision to have the surgery. This paper demonstrated the importance of patient involvement in the decision-making process.

Figaro, M. K., Russo, P. W., & Allegrante, J. P. (2004). Preferences for Arthritis Care Among Urban African Americans: 'I Don't Want to Be Cut'. *Health Psychology, 23,* 324-329.
Refid: 111578
Main messages:

- African-Americans have low expectations of surgery for arthritis.
- The reasons for negative expectations of surgery included that surgery was "hard to accept," could cause more problems, "doesn't last," is a method of "last resort" and introduces something "foreign" into the body that can be rejected.

Summary: This study examined beliefs among African-Americans about arthritis and surgery. The results found six themes that were related to participants' decisions to access surgery: their preference for natural remedies, negative expectations about surgery, beliefs about God's control, their preference for continuing in their current health condition, their relationships with specialists and fear of surgery or death.

Hudak, P. L., Clark, J. P., Hawker, G. A., Coyte, P. C., Mahomed, N. N., Kreder, H. J., & Wright, J. G. (2002). "You're perfect for the procedure! Why don't you want it?" Elderly arthritis patients' unwillingness to consider total joint arthroplasty surgery: a qualitative study. *Medical Decision Making, 22,* 272-278.
Refid: 112301
Main message:

- Elderly persons may have unique assumptions that affect their decisions about surgery. Some may opt against the procedure even if they are eligible candidates.

Summary: Seventeen elderly individuals who were potential candidates for TJA but were unwilling to undergo the procedure participated in an interview study about their decision-making process. The results showed that three assumptions might have prevented elderly persons from considering surgery: (1.) OA was a normal part of aging rather than a disease, (2.) only those with more severe pain and disability than themselves should have surgery, and (3.) if they either required or would benefit from TJA, their physicians would have suggested it.

Kroll, T. L., Richardson, M., Sharf, B. F., & SuarezAlmazor, M. E. (2007). "Keep on truckin'" or "It's got you in this little vacuum": race-based perceptions in decision-making for total knee arthroplasty. *Journal of Rheumatology, 34*, 1069-1075.
Refid: 133441
Main message:

- Patient attitudes and beliefs about TKA vary among ethnic groups. Differences in explanations of illness, changes in lifestyle, trust and skepticism, and paying for surgery are topics for discussion in the medical encounter.

Summary: This focus group study evaluated factors influencing preferences for TKA in patients with knee OA from different ethnic backgrounds. The results showed 30 distinct categories of information, 4 of which showed variations among ethnic groups. These differences included explanations of illness, changes in lifestyle, trust and skepticism, and paying for surgery. The authors concluded that there was a need for better patient-doctor communication around individual experiences and beliefs in an effort to support the patient's decision-making for TKA.

Powanda,M. C. (2003). The impatient patient: A personal view of osteoarthritis. *Inflammopharmacology, 11(4-6),* 317 – 322.
Refid: 134984
Main Message:

- A qualitative autobiographical account of dealing with osteoarthritis, and a call for more research into the biomechanics of this disease.

Summary: A qualitative account of one man's experience with osteoarthritis (OA), the process of obtaining a diagnosis and dealing with the symptoms. He talks about exercise, surgery medications, and the impact of pain and debilitation on his personal mental and emotional state as well as those of his friends and family. He implores for more research in the field of biomechanics which may lead to more effective painkillers and OA medications.

Radwin,L. E. (2008). Arthritis symptoms, information sources, and a constantly shifting threshold of risk-benefit ratios influenced elderly patients' decisions about total joint replacement., *Evidence-Based Nursing, 8(2),* 63.

Refid: 114092

Main message:

- Commentary on a study about the factors that influence elderly patients' decisions to undergo total joint replacement (TJR), stating that the information is useful to nurses who can tailor their information to the needs of the patient to help better prepare them to make decisions about elective surgery.

Summary: The author reflects on the paper by Clark et al which found that patients do not always fully understand the benefits and risks of proposed treatments. The author posits that nurses can provide educational content that is tailored to the specific patient, which is more useful than standardized educational content. Nurses who "know their patients" can also share experiential knowledge, and are well suited to provide advice about elective treatments based on the patient's values and needs.

Sanders, C., Donovan, J. L., & Dieppe, P. A. (2004). Unmet need for joint replacement: a qualitative investigation of barriers to treatment among individuals with severe pain and disability of the hip and knee. *Rheumatology, 43,* 353-357.
Refid: 114399
Main message:

- In the UK there are barriers to treatment and an unmet need for joint replacement, particularly for older people. Individuals' perceptions and past experiences with health care professionals may affect their decisions about joint replacement surgery.

Summary: In-depth qualitative interviews were carried out with 27 participants who had high levels of hip/knee pain and disability. Three types of barrier were identified: (1.) people's own perceptions of need and reluctance to seek treatment, (2.) perceptions and experiences of primary care and (3.) experiences of treatment in secondary care. Pessimism about the availability of treatments and concerns about the effectiveness and risks of surgery made older people reluctant to seek medical help. Some of those referred to a hospital specialist were told that they were too young or too mobile for surgery.

Tallon,D., Chard,J., Dieppe,P. (2000). Exploring the priorities of patients with osteoarthritis of the knee, *Arthritis Care & Research, 13(5),* 312 – 319.
Refid: 136106
Main Message:

- The lack of a patient-centered approach to care leads professionals to ignore key symptoms and issues for individuals, and to a preoccupation with pharmaceutical interventions, rather than the treatment options that their patients prefer.

Summary: A questionnaire was designed to explore the perceived importance of symptoms, treatment preferences, and research priorities of people with osteoarthritis (OA) of the knee, and was distributed to 112 people with knee OA. Pain, disability, and instability in the joint were the most important symptoms, and anxiety about knee OA caused distress to many people. Oral drugs (90%), physical therapy (62%), and aids and adaptations (56%) were the most commonly used treatments. Surgery, oral drugs, and intra-articular injections were perceived as the most efficacious interventions. Patients' highest priorities for research were surgery and educational interventions, despite the fact that few had had surgery and education was not perceived as very effective.

Taqui Shinshodia,H., Fujita,K., Makimoto,K., Hotokebuchi,T. (2006). Qualitative study of osteoarthritis patients" experience before and after total hip arthroplasty in Japan. *Nursing & health sciences, 8(2),* 81 – 87.
Refid: 136131
Main Messages:

- Although total hip arthroplasty has been shown to improve pain and disability, some patients also experience a decline in self-esteem and a change in self-image as a result of the procedure.

Summary: Qualitative interviews were used to investigate, describe, and analyze patients' experience before and after total hip arthroplasty (THA) in Japan. Twenty patients with OA who had undergone primary THA were recruited for this study. Participants reported dramatic improvements in pain and disability, however they also faced problems during the pre-operative period like those associated with abnormal posture. In the post-operative period, some people also suffered from distress over body image related to the artificial joint. Nursing interventions may be used to deal with these problems.

Toye, F. M., Barlow, J., Wright, C., & Lamb, S. E. (2006). Personal meanings in the construction of need for total knee replacement surgery. *Social science & medicine, 63,* 43-53.
Refid: 115072
Main message:

- The decision to undergo TKR is not related to symptoms alone, but also to personal meanings about the disease and its impact on the patient's life.

Summary: This was a qualitative study in which 18 semi-structured interviews were conducted with people who had enrolled for TKR and who had a lower-than-average disease burden based on pain and function scores. Several themes related to the need for TKR emerged: patients' adoption of the medical model of OA; patients' social network; the level of pain experienced; the impact of functional loss; patients' feelings of vulnerability, dependency, low mood and fatigue; and patients' ideas about disease progression and expectations of TKR outcomes. It is important for health professionals to explore and tackle these personal meanings when considering treatment.

Osteoarthritis: Surgery – quantitative studies (N=7)

Behairy, Y. M., Motuweh, S. H., & Kathlan, K. A. (2004). A survey of patients' attitude toward total knee replacement in a major center in the Kingdom of Saudi Arabia. *Saudi medical journal, 25,* 1291-1293.
Refid: 130451
Main message:

- Patient education is crucial for helping individuals make an informed decision about surgery.

Summary: The aim of this study, which was conducted through qualitative interviews with patients, was to evaluate patients' attitudes toward having total knee replacement (TKR) surgery and to identify factors that might influence their decisions. Their reasons for refusing surgery included the fear of failed surgery, or a memory of a previous failed surgery, and the dangers of TKR surgery; being afraid of stiffness or death or of being too old for surgery; worrying that their symptoms were not severe enough; and worrying about misinformation or the need for a second opinion. The results from this study showed a high refusal rate, but no specific influencing factor could be identified.

Byrne, M. M., Souchek, J., Richardson, M., & Suarez-Almazor, M. (2006). Racial/ethnic differences in preferences for total knee replacement surgery. *Journal of clinical epidemiology, 59,* 1078-1086.
Refid: 130920
Main message:

- Differences in knee replacement rates among ethnic groups may be partly due to differences in preferences for surgery.

Summary: This quantitative study examined the links between patients' ethnic background and their preferences for surgery versus medical treatment of knee osteoarthritis (OA). The results showed that African-Americans were significantly less likely to choose surgery than Caucasians were. Women and older individuals (of all ethnic backgrounds) were also less likely to choose surgery. There was no difference in preference for surgery between the general public and the patients examined in this study.

Figaro, M. K., Williams-Russo, P., & Allegrante, J. P. (2005). Expectation and outlook: the impact of patient preference on arthritis care among African Americans. *Journal of Ambulatory Care Management, 28,* 41-48.
Refid: 111576
Main message:

- African-Americans have low expectations of total knee replacement (TKR) and are less likely to consider TKR.

Summary: This survey investigated preferences among African-Americans with osteoarthritis (OA) regarding TKR surgery. Very few of the African-American patients interviewed believed that TKR was likely to improve knee pain, and almost half thought TKR would not improve their current health. African-American patients perceived a high quality of life, yet had low expectations from TKR and were therefore less likely to consider TKR as a treatment for OA.

Hawker,G. A. Guan,J. Croxford,R. Coyte,P. C. Glazier,R. H. Harvey,B. J. Wright,J. G. Williams,J. I. Badley,E. M. (2006). A prospective population-based study of the predictors of undergoing total joint arthroplasty. *Arthritis & Rheumatism, 54(10),* 3212 – 3220.
Refid: 132531
Main message:

- This prospective cohort study of people aged 55 years and older in Ontario, Canada found that the predictors of undergoing total joint arthroplasty (TJA) are: worse osteoarthritis (OA) symptoms, younger age, better health, and willingness to consider TJA.

Summary: This prospective cohort study included 2,128 people from an existing population-based cohort who were 55 years or older with disabling hip or knee OA and no prior TJA from two different regions in Ontario, Canada. The likelihood of undergoing TJA was significantly greater for people between the ages of 63 and 81, people with worse OA symptoms, people in better general health, and people who are willing to consider TJA. When willingness was excluded from the model, education level became significantly associated with receipt of TJA and there was a clear trend showing an increasing likelihood of TJA with more education. Sex and income were not significant predictors of TJA.

Ibrahim, S. A., Siminoff, L. A., Burant, C. J., & Kwoh, C. K. (2002). Differences in expectations of outcome mediate African American/white patient differences in "willingness" to consider joint replacement. *Arthritis & Rheumatism, 46,* 2429-2435.
Refid: 132804
Main message:

- African-American patients were less likely than Caucasian patients to express "willingness" to consider joint replacement even if the procedure was needed and recommended. This was explained by differences between the groups' expectations of surgery outcomes.

Summary: In a cross-sectional survey of 596 elderly men with moderate-to-severe symptomatic knee or hip OA, researchers found that African-American patients were less familiar with and less willing to consider joint replacement surgery than Caucasian patients. African-American patients were also more likely to expect a longer hospital stay, worse pain and more functional disability following replacement surgery. These findings help us understand some of the reasons for the marked racial/ethnic disparities in the use of joint replacement for knee/hip OA.

Suarez-Almazor, M. E., Souchek, J., Kelly, P. A., O'Malley, K., Byrne, M., Richardson, M., & Pak, C. (2005). Ethnic variation in knee replacement: patient preferences or uninformed disparity? *Archives of Internal Medicine, 165,* 1117-1124.
Refid: 136027
Main message:

- Ethnic minority patients with knee OA are less likely to consider TKR. This may be due to the patient's perception of benefit, lack of personal experiences with TKR, and lack of trust in health professionals.

Summary: A survey of 198 ethnically diverse patients with knee OA found that physicians had discussed TKR with 27% of African-Americans, 15% of Caucasians, and 11% of Hispanics. Caucasian patients were more likely than visible minority patients to have considered undergoing TKR, more likely to consider TKR if their OA worsened, and more likely to consider TKR as a beneficial procedure. Ethnic differences in treatment preferences remained after controlling for the effect of disease severity.

Swirtun, L. R., Eriksson, K., & Renstrom, P. (2006). Who chooses anterior cruciate ligament reconstruction and why? A 2-year prospective study. *Scandinavian journal of medicine & science in sports, 16,* 441-446.
Refid: 136068
Main message:

- The reason for most patients choosing to undergo early reconstruction (ER) was the assumption of future problems with the injured knee, rather than their current experience of with the knee function. However, the choice of undergoing late reconstruction (LR) appeared to be linked to the person's experience of the knee function.

Summary: Thirty-six patients with knee OA who chose anterior cruciate ligament reconstructive surgery were questioned about the reasons behind their decision. A high pre-injury activity level was associated with the choice of ACL reconstruction, but the choice of treatment was not associated with age, sex or the outcome variables measured. The 75% of the subjects who chose ER based their decision on assumptions of future problems rather than their knee function, and the 88% who chose reconstructive surgery later based their decision on their experience of knee function.

Osteoarthritis: Information – qualitative studies (N=4)

Baumann, M., Euller-Ziegler, L., & Guillemin, F. (2007). Evaluation of the expectations osteoarthritis patients have concerning healthcare, and their implications for practitioners. *Clinical & Experimental Rheumatology, 25,* 404-409.
Refid: 130418
Main message:

- Understanding patients' expectations is essential for improving the therapeutic process and patient care.

Summary: In this qualitative study, osteoarthritis patients were recruited and focus groups were conducted. The focus groups looked at patients' expectations of information about osteoarthritis; the attitudes of practitioners and communication between health professionals; and the support available from doctors, their family circle and society. The results suggested the patient-practitioner relationship could be improved if greater trust and better communication skills were developed, and if the practitioner were able to express sympathy. It was also suggested that general practitioners should act as mediators and facilitators to improve recognition and understanding of osteoarthritis by employers and public decision-makers.

Kroll, T. L., Richardson, M., Sharf, B. F., & SuarezAlmazor, M. E. (2007). "Keep on truckin'" or "It's got you in this little vacuum": race-based perceptions in decision-making for total knee arthroplasty. *Journal of Rheumatology, 34,* 1069-1075.
Refid: 133441
Main message:

- Patient attitudes and beliefs about TKA vary among ethnic groups. Differences in explanations of illness, changes in lifestyle, trust and skepticism, and paying for surgery are topics for discussion in the medical encounter.

Summary: This focus group study evaluated factors influencing preferences for TKA in patients with knee OA from different ethnic backgrounds. The results showed 30 distinct categories of information, 4 of which showed variations among ethnic groups. These differences included explanations of illness, changes in lifestyle, trust and skepticism, and paying for surgery. The authors concluded that there was a need for better patient-doctor communication around individual experiences and beliefs in an effort to support the patient's decision-making for TKA.

Mikhail, S. S., Zwar, N. A., Vagholkar, S., Dennis, S. M., & Day, R. O. (2007). Non-steroidal anti-inflammatory drugs in general practice: a decision-making dilemma. *Medical Journal of*

Australia, 187, 160-163.
Refid: 134294
Main message:

- There is a need to provide clear, unbiased information about non-steroidal anti-inflammatory drugs (NSAIDs) to help both GPs and patients negotiate the decision-making process.

Summary: Five focus groups (three for GPs and two for patients with OA) were conducted in southwestern Sydney, Australia, to examine decision-making about NSAIDs and to explore issues concerning the use of NSAIDs from both prescriber and consumer perspectives. The results showed that GPs are cautious when prescribing NSAIDs because of medicolegal concerns and uncertainty about their safety ; they were skeptical about information provided by the pharmaceutical industry because they found it confusing. Time was identified as a major barrier to adequate discussion with patients, and explaining the risk to patients in a meaningful way was perceived as a challenge. Patients wanted information and sought it from a range of sources, most commonly pharmacists and GPs. Most patients made active decisions about using or not using NSAIDs, with some favouring physical function over safety.

Powanda,M. C. (2003). The impatient patient: A personal view of osteoarthritis. *Inflammopharmacology, 11(4-6),* 317 – 322.
Refid: 134984
Main Message:

- A qualitative autobiographical account of dealing with osteoarthritis, and a call for more research into the biomechanics of this disease.

Summary: A qualitative account of one man's experience with osteoarthritis (OA), the process of obtaining a diagnosis and dealing with the symptoms. He talks about exercise, surgery medications, and the impact of pain and debilitation on his personal mental and emotional state as well as those of his friends and family. He implores for more research in the field of biomechanics which may lead to more effective painkillers and OA medications.

Osteoarthritis: Information – quantitative studies (N=4)

Cardiel, M. H. & Rojas-Serrano, J. (2002). Community-based study to estimate prevalence, burden of illness and help seeking behavior in rheumatic diseases in Mexico City. A COPCORD study. *Clinical & Experimental Rheumatology, 20,* 617-624.
Refid: 110792
Main message:

- A general practitioner treated 72% of patients with rheumatic diseases in Mexico City. Most patients responded well to the prescribed medication.

Summary: The purpose of this study was to estimate the prevalence of rheumatic diseases in a suburban community in Mexico City. The burden of illness and help-seeking behaviour of patients with rheumatic diseases were also examined. The results indicated that 419 participants (17%) had reported pain in the last seven days due to musculoskeletal disorders and 13% of the total sample had experienced some form of treatment.

Ibrahim,S. A., Siminoff,L. A., Burant,C. J., Kwoh,C. K. (2001). Variation in perceptions of

treatment and self-care practices in elderly with osteoarthritis: a comparison between African American and white patients., *Arthritis & Rheumatism (Arthritis Care & Research), 45(4),* 340 – 345.
Refid: 132807
Main Message:

- African American and Caucasian patients with osteoarthritis of the knee or hip differ with respect to their perceptions of traditional and complementary treatments for arthritis and their self-care practices.

Summary: This observational, cross-sectional study used structured questionnaires to compare the perceptions of the efficacy of traditional and complementary treatments and their self-care practices between elderly African American and Caucasian patients. The study sample consisted of 593 patients (44% African American and 56% Caucasian) from Ohio; the two groups were comparable with respect to age, disease severity or functional status, and comorbidities. African Americans were more likely to report lower educational level and household income than Caucasians. African Americans were also more likely to perceive various traditional and complementary care modalities as efficacious. However, they were less likely than Caucasians to perceive joint replacement therapy as efficacious, and more likely to rely on self-care measures for their arthritis.

Liu,Y., Doucette,W. R., Farris,K. B. (2007). Perceived difficulty and self-efficacy in the factor structure of perceived behavioral control to seek drug information from physicians and pharmacists. *Research in Social & Administrative Pharmacy: RSAP, 3(2),* 145 – 159.
Refid: 133742
Main Message:

- The concept of perceived behavioral control (PBC) in the Theory of Planned Behavior can be broken down into two dimensions: perceived difficulty and self-efficacy. Controllability impacts whether perceived difficulty and self-efficacy overlap or diverge, with higher controllability associated with distinct dimensions.

Summary: In the Theory of Planned Behavior, perceived behavioral control (PBC) has been directly measured in 3 different ways, i.e. perceived difficulty, self-efficacy, and controllability. This study explored the relationship of perceived difficulty and self-efficacy in the factor structure of PBC, and examined the impact of controllability on this relationship. The study context was osteoarthritis patients' drug information seeking from physicians and pharmacists for advertised anti-arthritic prescription medications. One thousand patients were randomly selected from 3000 nationwide osteoarthritis patients. A self-administered survey collected perceived difficulty (3 items), self-efficacy (3 items), and controllability (2 items) of drug information seeking from physicians and pharmacists. The response rate was 61.9%. Perceived difficulty and self-efficacy may represent 2 dimensions of an overall concept. Controllability impacts whether perceived difficulty and self-efficacy overlap or diverge, with higher controllability associated with distinct dimensions.

Liu, Y., Doucette, W. R., Farris, K. B., & Nayakankuppam, D. (2005). Drug information-seeking intention and behavior after exposure to direct-to-consumer advertisement of prescription drugs. *Research In Social & Administrative Pharmacy: RSAP, 1,* 251-269.
Refid: 113049
Main messages:

- Direct-to-consumer advertisements (DTCA) may prompt drug information-seeking, but do not influence decisions about treatment choices.
- Interventions could address patients' attitudes toward behavior, the influence of their important others and their role as information seeker.

Summary: The purpose of the survey was to identify predictors of patients' intentions and behaviours to seek drug information from physicians, pharmacists and the Internet after exposure to direct-to-consumer marketing using theories of planned behavior (TPB) and self-efficacy. The questionnaire was sent to 1,000 patients. Of those, 454 had prior exposure to DTCA. The results showed that TPB accounted for 40-50% of the variance for patients' intentions to seek drug information, and 19-38% of the variance for the action of drug information-seeking.

General arthritis: Diagnosis – qualitative studies (N=4)

Drew, D. & Hewitt, H. (2006). A qualitative approach to understanding patients' diagnosis of Lyme disease. *Public Health Nursing, 23,* 20-26.
Refid: 111333
Main message:

- Participants are frustrated during the time leading up to their diagnosis.

Summary: This study used individual interviews to explore the experience of being diagnosed with Lyme disease. Participants were frustrated after seeing multiple health care providers and having many tests done. They felt relieved when a diagnosis was made and were hopeful for their future.

Hale,E. D., Treharne,G. J. Lyons,A. C., Norton,Y., Mole,S., Mitton,D. L., Douglas,K. M., Erb,N., Kitas,G. D. (2005). "Joining the dots" for patients with systemic lupus erythematosus: personal perspectives of health care from a qualitative study. *Annals of the Rheumatic Diseases, 65(5),* 585 – 589.
Refid: 141135
Main Message:

- Patients living with systemic lupus erythematosus (SLE) in the United Kingdom do not feel that their condition is well-understood by all if their health care providers or people close to them. Increased communication between various health professionals and readily available information about SLE may help to minimize patients' feelings of isolation.

Summary: Semi-structured interviews were conducted with 10 women aged 26 to 68 years who were diagnosed with SLE 1 to 12 years earlier. Four themes emerged: diagnostic difficulties; understanding; communication; and integrated health care. Before diagnosis there was concern to appear legitimately ill and to have a label for the condition. After diagnosis participants still encountered health care professionals who were poorly informed about SLE. Family, friends, and employers did not understand the fluctuating nature of SLE, which often led to isolation. Participants felt that even health care professionals who specialized in SLE could not fully understand the psychosocial impact of the condition, and therefore did not provide information to meet those needs. Participants did not know which of the many health care professionals they had contact with to approach about their concerns. Lack of communication at an interdisciplinary level left them feeling that nobody was "joining the dots" for their health care.

Headland, M. (2006). Using a website containing patient narratives to understand people's experiences of living with arthritis. *Journal of Orthopaedic Nursing, 10,* 106-112.
Refid: 123404
Main message:

- The main concerns of people with arthritis in the UK include a lack of engagement and adequate treatment by health professionals and health care staff, delays in obtaining a diagnosis and beginning treatment, and effects of the illness on personal relationships.

Summary: A thematic analysis of patients' written comments about their experiences of living with arthritis posted on the BBC's health website was used to explore people's personal experiences of living with arthritis. The findings illustrated how the respondents used various psychological and behavioural mechanisms to help them cope and adjust to the changes brought about by their condition. Some respondents indicated that they were dissatisfied with the care and attention they received from health care professionals, while others spoke of more positive experiences. Another important issue was the wait time for obtaining a diagnosis and the corresponding effects this had on the patient's treatment and outcome. The health care professionals' attitudes toward the patients and their symptoms played a significant role in this process. Social implications and effects on personal relationships were also highlighted.

Maddox, J. (1981). Medical care and the arthritis sufferer: a survey in outer Melbourne. *Australian Family Physician, 10,* 876-882.
Refid: 113156
Main message:

- Rheumatic diseases are undertreated in Melbourne, Australia.

Summary: Chronic rheumatic diseases affect more than 750,000 Australians, who consume medical services at least in proportion to their numbers. A survey of 646 people with a rheumatic complaint in Ringwood, Victoria, found consistent accounts by sufferers of unmet expectations and shortcomings in medical care. While it is possible that dissatisfaction is inevitable because there are no effective treatments for arthritis, the author argues that there was a consistent and widespread belief among respondents that physicians' medical knowledge of arthritis was limited or incomplete, that their general outlook on the management of rheumatic disease was pessimistic, and that more research and education in arthritis was needed.

General arthritis: Diagnosis – quantitative studies (N=3)

Chipperfield, J. G. & Greenslade, L. (1999). Perceived control as a buffer in the use of health care services. *Journals of Gerontology Series B-Psychological Sciences & Social Sciences, 54,* 146-154.
Refid: 110898
Main message:

- Patients with low levels of perceived control (the ability to influence outcomes and events in the environment) use health services more often than patients with high levels of perceived control.

Summary: The purpose of this study was to examine the link between perceived control and patterns of health service use among older people with arthritis. Individuals who perceived low levels of control were found to use more health services than their high-control counterparts;

they visited their physicians more often, had more laboratory tests, and stayed longer in the hospital. This was true only for those who reported being restricted by their arthritis.

Dubbert, M. L., Sharp, G. C., Kay, D. R., Sylvester, J. L., & Brownson, R. C. (1990). Implications of a statewide survey of arthritis in Missouri. *Missouri medicine, 87,* 145-148.
Refid: 111342
<u>Main message:</u>

- Most of the survey participants, all had arthritis, were misinformed and lacked knowledge about their condition. Television, newspapers and magazines were identified as the most popular sources of information about arthritis.

<u>Summary:</u> This study involved a random sample of 2,533 households contacted by phone for a survey about their knowledge of arthritis. The response rate was 68% and approximately one out of four respondents had arthritis. The majority of participants did not know the difference between the common types of arthritis, their causes and their treatments. They also felt that a person should only seek help when their symptoms were severe. The media was identified as the most effective way to obtain information about the disease.

Maisiak, R., Koplon, S., & Heck, L. W. (1990). Subsequent behavior of users of an arthritis information telephone service. *Arthritis & Rheumatism, 33,* 212-218.
Refid: 113197
<u>Main message</u>:

- The use of telephone information services may increase subsequent positive actions taken and the sense of control in people with arthritis.

<u>Summary</u>: Follow-up telephone interviews were conducted with a random sample of 305 users of a prototype telephone information service for arthritis two to four months after their initial contact with the service. Of those surveyed, 79% reported taking at least one positive action for their arthritis because of service usage. The most frequently reported actions were asking the doctor more questions and greater compliance with the doctor's orders. About half of the respondents felt more in control of their arthritis because of service usage. Respondents who were younger than 60 years old, black or symptomatic were significantly more likely to take an action. This minimal intervention may stimulate positive behaviours for individuals with arthritis.

General arthritis: Diagnosis – mixed methods (N=1)

Kramer, B. J., Harker, J. O., & Wong, A. L. (2002). Arthritis beliefs and self-care in an Urban American Indian population. *Arthritis Care and Research, 47,* 588-594.
Refid: 112764
<u>Main message</u>:

- Chronic arthritis pain may not be optimally managed in the Native American population and clinicians should recognize that patients may understate serious symptoms.

<u>Summary</u>: In-depth qualitative interviews were conducted with a convenience sample of urban-dwelling Native Americans. Joint pain was not generally assumed to be related to arthritis or to aging. The belief that chronic pain affecting multiple joints was a serious and unexpected condition was associated with Native Americans' decisions to seek medical attention. The

researchers found that verbal communications about pain might be subtle or underemphasized in this population and that their coping strategies for chronic or episodic pain were limited.

General arthritis: Medication – qualitative studies (N=7)

Bournes,D. A. (2000). A commitment to honoring people's choices, *Nursing science quarterly*, *13(1)*,18 – 23.
Refid: 150286
Main Messages:

- The "human becoming" school of thought posits that individuals should make their own decisions about their healthcare. This is a more ethical model of care that should replace the traditional paternalistic model.

Summary: A belief that in certain circumstances it is acceptable to disregard a person's views in favor of promoting his or her health is called *paternalism*. In contrast, the "human becoming" school of thought posits that the person is the only one who knows the way – thus, individuals' own decisions about their health and quality of life are believed to be the most appropriate guides for healthcare practices. To judge people as not knowing what is best for their lives may lead to ways of practicing that disregard individuals' uniqueness, discount individuals' choices, and violate individuals' right to self-determination. The purposes of this article are to specify various meanings of paternalism, illuminate the ethical framework for honoring people's choices that is embedded in the ontology of the human becoming school of thought, and demonstrate the difference between practice guided by paternalistic values and beliefs and practice guided by "human becoming".

Erickson, B. E. (2007). Radioactive pain relief: Health care strategies and risk assessment among elderly persons with arthritis at radon health mines. *Journal of Alternative and Complementary Medicine*, *13*, 375-379.
Refid: 111437
Main messages:

- Participants believed that radon therapy is an acceptable choice of treatment for arthritis.
- Fear of the possible health risks had little influence on the decision-making process for the study participants.

Summary: The purpose of this qualitative study was to examine the use of radioactive radon therapy by people with arthritis. Participants described their perceptions of the benefits of radon therapy, which included pain relief, fewer side effects, lower cost and increased quality of life. The risk of lung cancer from radon exposure was diminished in their perception when compared to the perceived benefits.

Hale,E. D., Treharne,G. J. Lyons,A. C., Norton,Y., Mole,S., Mitton,D. L., Douglas,K. M., Erb,N., Kitas,G. D. (2005). "Joining the dots" for patients with systemic lupus erythematosus: personal perspectives of health care from a qualitative study. *Annals of the Rheumatic Diseases*, *65(5)*, 585 – 589.
Refid: 141135
Main Message:

- Patients living with systemic lupus erythematosus (SLE) in the United Kingdom do not feel that their condition is well-understood by all if their health care providers or people close to them. Increased communication between various health professionals and readily available information about SLE may help to minimize patients' feelings of isolation.

Summary: Semi-structured interviews were conducted with 10 women aged 26 to 68 years who were diagnosed with SLE 1 to 12 years earlier. Four themes emerged: diagnostic difficulties; understanding; communication; and integrated health care. Before diagnosis there was concern to appear legitimately ill and to have a label for the condition. After diagnosis participants still encountered health care professionals who were poorly informed about SLE. Family, friends, and employers did not understand the fluctuating nature of SLE, which often led to isolation. Participants felt that even health care professionals who specialized in SLE could not fully understand the psychosocial impact of the condition, and therefore did not provide information to meet those needs. Participants did not know which of the many health care professionals they had contact with to approach about their concerns. Lack of communication at an interdisciplinary level left them feeling that nobody was "joining the dots" for their health care.

Maddox, J. (1981). Medical care and the arthritis sufferer: a survey in outer Melbourne. *Australian Family Physician, 10,* 876-882.
Refid: 113156
Main message:

- Rheumatic diseases are undertreated in Melbourne, Australia.

Summary: Chronic rheumatic diseases affect more than 750,000 Australians, who consume medical services at least in proportion to their numbers. A survey of 646 people with a rheumatic complaint in Ringwood, Victoria, found consistent accounts by sufferers of unmet expectations and shortcomings in medical care. While it is possible that dissatisfaction is inevitable because there are no effective treatments for arthritis, the author argues that there was a consistent and widespread belief among respondents that physicians' medical knowledge of arthritis was limited or incomplete, that their general outlook on the management of rheumatic disease was pessimistic, and that more research and education in arthritis was needed.

O'Day, B., Dautel, P., & Scheer, J. (2002). Barriers to healthcare for people with mobility impairments. *Managed care quarterly, 10,* 41-51.
Refid: 125931
Main message:

- Common barriers to accessing health care exist for people with mobility impairments. In order to improve the care of these patients, the barriers must be addressed and eliminated.

Summary: Focus groups were used to determine the barriers to health care that people with mobility impairments, including spinal cord injury, cerebral palsy, multiple sclerosis and arthritis, face. The results revealed common barriers such as restricted physical access to doctors' offices and office equipment; difficulty establishing trusting relationships with physicians; and the costs of durable medical equipment, medications and rehabilitation.

Garcia Popa-Lisseanu, M. G., Greisinger, A., Richardson, M., O'Malley, K. J., Janssen, N. M., Marcus, D. M., Tagore, J., & Suarez-Almazor, M. E. (2005). Determinants of treatment adherence in ethnically diverse, economically disadvantaged patients with rheumatic disease. *Journal of Rheumatology, 32*, 913-919.

Refid: 122724

Main message:

- The main barriers to adherence to treatment are fear of side effects, financial problems, difficulty in navigating the public health system, and perceived treatment inefficacy.

Summary: This study aimed to examine the factors that affect adherence to medical recommendations among ethnically diverse and economically disadvantaged patients with RA and systemic lupus erythematosus (SLE) in Houston, Texas. The majority of participants reported experiencing difficulty in adhering to their treatment. Patients with SLE or RA reported similar barriers to adhering to treatment and to keeping appointments. The authors concluded that patients' perceptions of, and experiences with, the health system influenced their adherence to treatment.

Zhang, J. & Verhoef, M. J. (2002). Illness management strategies among Chinese immigrants living with arthritis. *Social science & medicine, 55,* 1795-1802.

Refid: 115562

Main message:

- Chinese immigrants in Canada tend to manage their arthritis symptoms on their own before seeing a physician. Some may also see a Chinese medicine practitioner, but most of them will return to Western medicine later on.

Summary: This was a qualitative study in which in-depth interviews were conducted with 19 Chinese immigrants in Calgary, Canada. The results indicated that the process of illness management usually started with participants using self-care remedies, before consulting Western physicians, then consulting Chinese healers, and finally returning to Western medicine. Disease management strategies among Chinese immigrants are influenced by disease, personal and cultural factors. These factors could influence possible approaches for providing culturally sensitive care, which can lead to greater satisfaction and well-being for Chinese immigrants with arthritis.

General arthritis: Medication – quantitative studies (N=7)

Blake, V. A., Allegrante, J. P., Robbins, L., Mancuso, C. A., Peterson, M. G., Esdaile, J. M., Paget, S. A., & Charlson, M. E. (2002). Racial differences in social network experience and perceptions of benefit of arthritis treatments among New York City Medicare beneficiaries with self-reported hip and knee pain. *Arthritis & Rheumatism, 47,* 366-371.

Refid: 110493

Main messages:

- The choice of whether or not to have surgery as a treatment option for arthritis appears to vary by race.
- The perception of risk of surgery is much higher among African-Americans compared to Caucasians and is a barrier when considering surgery.

Summary: This quantitative study examined social networks and perceptions of the benefit of arthritis treatments and whether they influenced a decision to seek diagnosis and treatment. The results showed that African-Americans know fewer people who have had surgical treatment of hip and knee pain than Caucasians do and appear to be less likely to perceive such treatment as beneficial.

Chipperfield, J. G. & Greenslade, L. (1999). Perceived control as a buffer in the use of health care services. *Journals of Gerontology Series B-Psychological Sciences & Social Sciences, 54,* 146-154.
Refid: 110898
Main message:

- Patients with low levels of perceived control (the ability to influence outcomes and events in the environment) use health services more often than patients with high levels of perceived control.

Summary: The purpose of this study was to examine the link between perceived control and patterns of health service use among older people with arthritis. Individuals who perceived low levels of control were found to use more health services than their high-control counterparts; they visited their physicians more often, had more laboratory tests, and stayed longer in the hospital. This was true only for those who reported being restricted by their arthritis.

Lazarus, H. & Neumann, C. J. (2001). Assessing undertreatment of pain: the patients' perspectives. *Journal of Pharmaceutical Care in Pain & Symptom Control, 9,* 5-34.
Refid: 112892
Main message:

- Pain among patients with chronic diseases such as arthritis is undertreated.

Summary: An in-depth qualitative interview survey was conducted with 1,000 persons living at home with pain due to a medical condition to assess their attitudes toward pain, medications and their doctors, as well as to identify the size and scope of undertreatment. Of those interviewed, 90% had seen a physician, 67% were under a doctor's care, 86% saw the same clinician for the pain and its cause, 50% saw a general practitioner or family physician, 13% had seen a pain specialist, 42% said their prescription analgesic was less than very effective, 67% indicated that their daily lives had been altered by pain and 51% said they could not remember what it felt like not to be in pain.

Maisiak, R., Koplon, S., & Heck, L. W. (1990). Subsequent behavior of users of an arthritis information telephone service. *Arthritis & Rheumatism, 33,* 212-218.
Refid: 113197
Main message:

- The use of telephone information services may increase subsequent positive actions taken and the sense of control in people with arthritis.

Summary: Follow-up telephone interviews were conducted with a random sample of 305 users of a prototype telephone information service for arthritis two to four months after their initial contact with the service. Of those surveyed, 79% reported taking at least one positive action for their arthritis because of service usage. The most frequently reported actions were asking the doctor more questions and greater compliance with the doctor's orders. About half of the respondents felt more in control of their arthritis because of service usage. Respondents who were younger than 60 years old, black or symptomatic were significantly more likely to take an action. This minimal intervention may stimulate positive behaviours for individuals with arthritis.

Mauksch, L. B., Katon, W. J., Russo, J., Tucker, S. M., Walker, E., & Cameron, J. (2003). The content of a low-income, uninsured primary care population: Including the patient agenda. *Journal of the American Board of Family Practice, 16,* 278-289.
Refid: 113316
Main message:

- A survey of primary care clinic patients in an uninsured, low-income population of Colorado showed that their health issues consisted mostly of physical pain and emotional distress. These needs place a serious burden on providers and can complicate the management of patients' chronic medical illnesses.

Summary: A survey was conducted with 500 consecutive patients in a primary care clinic serving only uninsured, low-income patients. Participants reported that their most common chronic medical problems were headaches, chronic back problems and arthritis. The most common concerns patients wanted to discuss with health care providers were emotional issues. When compared with patients without mental illness, those with a current major mental illness reported significantly more concerns about their health, physical symptoms, chronic illnesses, stressors and higher incidences of abuse during their life.

Vetter, N. J., Charny, M., Lewis, P. A., & Farrow, S. (1990). Prevalence and treatment of symptoms of rheumatism and arthritis among over 65 year olds: a community profile. *British Journal of General Practice, 40,* 69-71.
Refid: 115220
Main message:

- Arthritis and rheumatism are common among people aged 65 years and over, especially in women, but many people with symptoms had not reported them to a health professional.

Summary: This survey involved a random sample of 712 people aged 65 years and over in the UK. Symptoms of arthritis and rheumatism were very common, more so in women than in men, and were associated with marked degrees of disability and some dependency. While most respondents regarded their general practitioner as the best person to treat such symptoms, many had not reported them to any health service personnel, but had chosen instead to treat them themselves, suggesting a degree of skepticism about the effectiveness of professional treatment.

Ware, M. A., Adams, H., & Guy, G. W. (2005). The medicinal use of cannabis in the UK: Results of a nationwide survey. *International journal of clinical practice, 59,* 291-295.
Refid: 115300
Main message:

- In the UK medicinal cannabis is used by up to 55% of people, especially in younger people (both male and female) and older males, with chronic conditions including arthritis.

Summary: A self-administered questionnaire study of 2,969 people in which subjects were self-selected was conducted in the UK. Medicinal cannabis use was reported by patients with chronic pain, multiple sclerosis, depression, arthritis and neuropathy. Medicinal cannabis use was associated with youth, males and previous recreational use. Researchers advised caution on the interpretation of these data because the study population was self-selected rather than randomly selected, which introduces a risk of selection bias in the results. They recommended that further clinical studies were required to target people who have never used or rarely use cannabis in order to determine the effectiveness of cannabis for pain management.

General arthritis: Allied health – qualitative studies (N=3)

Hale,E. D., Treharne,G. J. Lyons,A. C., Norton,Y., Mole,S., Mitton,D. L., Douglas,K. M., Erb,N., Kitas,G. D. (2005). "Joining the dots" for patients with systemic lupus erythematosus: personal perspectives of health care from a qualitative study. *Annals of the Rheumatic Diseases, 65(5),* 585 – 589.
Refid: 141135
Main Message:

- Patients living with systemic lupus erythematosus (SLE) in the United Kingdom do not feel that their condition is well-understood by all if their health care providers or people close to them. Increased communication between various health professionals and readily available information about SLE may help to minimize patients' feelings of isolation.

Summary: Semi-structured interviews were conducted with 10 women aged 26 to 68 years who were diagnosed with SLE 1 to 12 years earlier. Four themes emerged: diagnostic difficulties; understanding; communication; and integrated health care. Before diagnosis there was concern to appear legitimately ill and to have a label for the condition. After diagnosis participants still encountered health care professionals who were poorly informed about SLE. Family, friends, and employers did not understand the fluctuating nature of SLE, which often led to isolation. Participants felt that even health care professionals who specialized in SLE could not fully understand the psychosocial impact of the condition, and therefore did not provide information to meet those needs. Participants did not know which of the many health care professionals they had contact with to approach about their concerns. Lack of communication at an interdisciplinary level left them feeling that nobody was "joining the dots" for their health care.

O'Day, B., Dautel, P., & Scheer, J. (2002). Barriers to healthcare for people with mobility impairments. *Managed care quarterly, 10,* 41-51.
Refid: 125931
Main message:

- Common barriers to accessing health care exist for people with mobility impairments. In order to improve the care of these patients, the barriers must be addressed and eliminated.

Summary: Focus groups were used to determine the barriers to health care that people with mobility impairments, including spinal cord injury, cerebral palsy, multiple sclerosis and arthritis, face. The results revealed common barriers such as restricted physical access to doctors' offices and office equipment; difficulty establishing trusting relationships with physicians; and the costs of durable medical equipment, medications and rehabilitation.

Zhang, J. & Verhoef, M. J. (2002). Illness management strategies among Chinese immigrants living with arthritis. *Social science & medicine, 55,* 1795-1802.
Refid: 115562
Main message:

- Chinese immigrants in Canada tend to manage their arthritis symptoms on their own before seeing a physician. Some may also see a Chinese medicine practitioner, but most of them will return to Western medicine later on.

Summary: This was a qualitative study in which in-depth interviews were conducted with 19 Chinese immigrants in Calgary, Canada. The results indicated that the process of illness management usually started with participants using self-care remedies, before consulting Western physicians, then consulting Chinese healers, and finally returning to Western medicine. Disease management strategies among Chinese immigrants are influenced by disease, personal and cultural factors. These factors could influence possible approaches for providing culturally sensitive care, which can lead to greater satisfaction and well-being for Chinese immigrants with arthritis.

General arthritis: Allied health – quantitative studies (N=10)

Blake, V. A., Allegrante, J. P., Robbins, L., Mancuso, C. A., Peterson, M. G., Esdaile, J. M., Paget, S. A., & Charlson, M. E. (2002). Racial differences in social network experience and perceptions of benefit of arthritis treatments among New York City Medicare beneficiaries with self-reported hip and knee pain. *Arthritis & Rheumatism, 47,* 366-371.
Refid: 110493
Main messages:

- The choice of whether or not to have surgery as a treatment option for arthritis appears to vary by race.
- The perception of risk of surgery is much higher among African-Americans compared to Caucasians and is a barrier when considering surgery.

Summary: This quantitative study examined social networks and perceptions of the benefit of arthritis treatments and whether they influenced a decision to seek diagnosis and treatment. The results showed that African-Americans know fewer people who have had surgical treatment of hip and knee pain than Caucasians do and appear to be less likely to perceive such treatment as beneficial.

Centers for Disease Control and Prevention (CDC) (2003). Adults who have never seen a health-care provider for chronic joint symptoms--United States, 2001. *MMWR - Morbidity & Mortality Weekly Report, 52,* 416-419.
Refid: 110828
Main message:

- One in five people with chronic joint symptoms are not seeking treatment for their joint symptoms.

Summary: The purpose of this CDC report was to estimate the prevalence of people with chronic joint symptoms who did not see a health care provider in 2001. The results indicated that one-fifth of the estimated population had never seen a health care provider for joint pain problems. Several factors contribute to these findings. For example, many patients have comorbidities that were more severe or life-threatening then their joint symptoms and so they might pay less attention to the latter. Also, some patients perceived arthritis as being part of the normal aging process and so felt that treatment was neither necessary nor beneficial.

Chipperfield, J. G. & Greenslade, L. (1999). Perceived control as a buffer in the use of health care services. *Journals of Gerontology Series B-Psychological Sciences & Social Sciences, 54,* 146-154.
Refid: 110898
Main message:

- Patients with low levels of perceived control (the ability to influence outcomes and events in the environment) use health services more often than patients with high levels of perceived control.

Summary: The purpose of this study was to examine the link between perceived control and patterns of health service use among older people with arthritis. Individuals who perceived low levels of control were found to use more health services than their high-control counterparts; they visited their physicians more often, had more laboratory tests, and stayed longer in the hospital. This was true only for those who reported being restricted by their arthritis.

Dubbert, M. L., Sharp, G. C., Kay, D. R., Sylvester, J. L., & Brownson, R. C. (1990). Implications of a statewide survey of arthritis in Missouri. *Missouri medicine, 87,* 145-148.
Refid: 111342
Main message:

- The majority of patients with arthritis who were surveyed in this study were misinformed and lacked knowledge about their condition. Television, newspapers and magazines were identified as the most popular sources of information about arthritis.

Summary: This study involved a random sample of 2,533 households contacted by phone for a survey about their knowledge of arthritis. The response rate was 68% and approximately one out of four respondents had arthritis. The majority of participants did not know the difference between the common types of arthritis, their causes and their treatments. They also felt that a person should only seek help when their symptoms were severe. The media was identified as the most effective way to obtain information about the disease.

Kim, H. A., Bae, Y. D., & Seo, Y. I. (2004). Arthritis information on the Web and its influence on patients and physicians: a Korean study. *Clinical & Experimental Rheumatology, 22,* 49-54.
Refid: 112628
Main message:

- An analysis of Korean arthritis websites revealed many sites with financial interests and a discrepancy between patients and physicians regarding the impact of Web-sourced arthritis information on the doctor-patient relationship.

Summary: Questionnaire surveys of patients with arthritis and rheumatologists were performed to appraise the impact of arthritis information available on the Web. Among 257 patients surveyed, 28% reported that they searched for arthritis information on the Web. Factors associated with using the Web for arthritis information were youth, employment and having a higher income and higher level of education. While the difference in ratings regarding the accuracy of Web-sourced arthritis information between physicians and patients was not significant, only about 16% of physicians responded that their patients understood the Internet content accurately. Physicians also tended to reply more negatively than patients about the content and the influence of Web-sourced arthritis information.

Kjeken, I., Dagfinrud, H., Mowinckel, P., Uhlig, T., Kvien, T. K., & Finset, A. (2006).

Rheumatology care: Involvement in medical decisions, received information, satisfaction with care, and unmet health care needs in patients with rheumatoid arthritis and ankylosing spondylitis. *Arthritis & Rheumatism, 55,* 394-401.
Refid: 124337
Main message:

- There is a need for a more flexible and patient-centred care model in which patients with RA or ankylosing spondylitis can decide which services they need and how they should be delivered.

Summary: Questionnaires were completed by 1,193 patients with RA and ankylosing spondylitis. The majority of patients reported medium to high levels of information received about RA, involvement in medical decisions and satisfaction with care. High involvement in medical decisions was associated with high levels of perceived information and satisfaction, as well as with lower age and a good health status. Patient satisfaction, a high level of received information, age and 12+ years of formal education were significant predictors to current involvement. Nearly one-third of the respondents reported a variety of unmet health care needs, and this report was associated with poor health.

Lazarus, H. & Neumann, C. J. (2001). Assessing undertreatment of pain: the patients' perspectives. *Journal of Pharmaceutical Care in Pain & Symptom Control, 9,* 5-34.
Refid: 112892
Main message:

- Pain among patients with chronic diseases such as arthritis is undertreated.

Summary: An in-depth qualitative interview survey was conducted with 1,000 persons living at home with pain due to a medical condition to assess their attitudes toward pain, medications and their doctors, as well as to identify the size and scope of undertreatment. Of those interviewed, 90% had seen a physician, 67% were under a doctor's care, 86% saw the same clinician for the pain and its cause, 50% saw a general practitioner or family physician, 13% had seen a pain specialist, 42% said their prescription analgesic was less than very effective, 67% indicated that their daily lives had been altered by pain and 51% said they could not remember what it felt like not to be in pain.

Maisiak, R., Koplon, S., & Heck, L. W. (1990). Subsequent behavior of users of an arthritis information telephone service. *Arthritis & Rheumatism, 33,* 212-218.
Refid: 113197
Main message:

- The use of telephone information services may increase subsequent positive actions taken and the sense of control in people with arthritis.

Summary: Follow-up telephone interviews were conducted with a random sample of 305 users of a prototype telephone information service for arthritis two to four months after their initial contact with the service. Of those surveyed, 79% reported taking at least one positive action for their arthritis because of service usage. The most frequently reported actions were asking the doctor more questions and greater compliance with the doctor's orders. About half of the respondents felt more in control of their arthritis because of service usage. Respondents who were younger than 60 years old, black or symptomatic were significantly more likely to take an action. This minimal intervention may stimulate positive behaviours for individuals with arthritis.

Mauksch, L. B., Katon, W. J., Russo, J., Tucker, S. M., Walker, E., & Cameron, J. (2003). The content of a low-income, uninsured primary care population: Including the patient agenda. *Journal of the American Board of Family Practice, 16,* 278-289.
Refid: 113316
Main message:

- A survey of primary care clinic patients in an uninsured, low-income population of Colorado showed that their health issues consisted mostly of physical pain and emotional distress. These needs place a serious burden on providers and can complicate the management of patients' chronic medical illnesses.

Summary: A survey was conducted with 500 consecutive patients in a primary care clinic serving only uninsured, low-income patients. Participants reported that their most common chronic medical problems were headaches, chronic back problems and arthritis. The most common concerns patients wanted to discuss with health care providers were emotional issues. When compared with patients without mental illness, those with a current major mental illness reported significantly more concerns about their health, physical symptoms, chronic illnesses, stressors and higher incidences of abuse during their life.

Saag, K. G., Doebbeling, B. N., Rohrer, J. E., Kolluri, S., Mitchell, T. A., & Wallace, R. B. (1998). Arthritis health service utilization among the elderly: The role of urban-rural residence and other utilization factors. *Arthritis Care and Research, 11,* 177-185.
Refid: 126901
Main message:

- There is a consistent association of need factors, joint swelling and a diagnosis of RA with physician utilization. Urban/rural status does not appear to independently influence the use of health care providers for arthritis care.

Summary: A population-based telephone interview survey was conducted on a random sample of 488 adults aged 65 or older with self-reported arthritis, with about half the sample from urban communities and half from rural communities. The results indicated that urban respondents were more commonly reported as having received a diagnosis of osteoarthritis from their physicians but being less likely to report RA. A greater proportion of urban versus rural respondents had seen a physician for their arthritis and had seen an orthopaedist or general internist more often. Some factors were significantly associated with prior rheumatologist use; for example, diagnosis of RA, being younger, living with someone, having a higher income and being further from an arthritis care provider.

General arthritis: CAT – qualitative studies (N=4)

Erickson, B. E. (2007). Radioactive pain relief: Health care strategies and risk assessment among elderly persons with arthritis at radon health mines. *Journal of Alternative and Complementary Medicine, 13,* 375-379.
Refid: 111437
Main messages:

- Participants believed that radon therapy is an acceptable choice of treatment for arthritis.

- Fear of the possible health risks had little influence on the decision-making process for the study participants.

Summary: The purpose of this qualitative study was to examine the use of radioactive radon therapy by people with arthritis. Participants described their perceptions of the benefits of radon therapy, which included pain relief, fewer side effects, lower cost and increased quality of life. The risk of lung cancer from radon exposure was diminished in their perception when compared to the perceived benefits.

Fadlon, J. (2004). Unrest in Utopia: Israeli Patients' Dissatisfaction with Non-Conventional Medicine. *Social science & medicine, 58,* 2421-2429.
Refid: 111483
Main message:

- The findings show that all patients in this study decided to abandon treatment if it did not meet their expectations for a cure.

Summary: This qualitative paper explored patients' dissatisfaction with non-conventional therapies. Three main topics emerged from the patient interviews: patients generally did not like having a paternalistic relationship with the doctor; patients often felt that the alternative therapies were no different to conventional medicine; and treatment outcome is the first consideration when deciding whether or not to commit to the treatment. Concepts such as "smart consumers," who place utmost importance on outcome and do not hesitate to discontinue treatment, were also discussed.

O'Day, B., Dautel, P., & Scheer, J. (2002). Barriers to healthcare for people with mobility impairments. *Managed care quarterly, 10,* 41-51.
Refid: 125931
Main message:

- Common barriers to accessing health care exist for people with mobility impairments. In order to improve the care of these patients, the barriers must be addressed and eliminated.

Summary: Focus groups were used to determine the barriers to health care that people with mobility impairments, including spinal cord injury, cerebral palsy, multiple sclerosis and arthritis, face. The results revealed common barriers such as restricted physical access to doctors' offices and office equipment; difficulty establishing trusting relationships with physicians; and the costs of durable medical equipment, medications and rehabilitation.

Zhang, J. & Verhoef, M. J. (2002). Illness management strategies among Chinese immigrants living with arthritis. *Social science & medicine, 55,* 1795-1802.
Refid: 115562
Main message:

- Chinese immigrants in Canada tend to manage their arthritis symptoms on their own before seeing a physician. Some may also see a Chinese medicine practitioner, but most of them will return to Western medicine later on.

Summary: This was a qualitative study in which in-depth interviews were conducted with 19 Chinese immigrants in Calgary, Canada. The results indicated that the process of illness management usually started with participants using self-care remedies, before consulting Western physicians, then consulting Chinese healers, and finally returning to Western medicine.

Disease management strategies among Chinese immigrants are influenced by disease, personal and cultural factors. These factors could influence possible approaches for providing culturally sensitive care, which can lead to greater satisfaction and well-being for Chinese immigrants with arthritis.

General arthritis: CAT – quantitative studies (N=11)

Ang, D. C., Ibrahim, S. A., Burant, C. J., Siminoff, L. A., & Kwoh, C. K. (2002). Ethnic differences in the perception of prayer and consideration of joint arthroplasty. *Medical care, 40,* 471-476.
Refid: 110160
Main message:

- Patients' perceptions of the benefits of prayer may influence their decisions about surgery.

Summary: This quantitative study examined ethnic differences in the perception and use of prayer in the treatment of arthritis and its role in patients' decision-making about surgery. It aimed to measure the "helpfulness of prayer" in the treatment of arthritis and patients' attitudes toward joint arthroplasty. The results demonstrated that African-American patients were more likely than Caucasian patients to perceive prayer as helpful and that they were more likely to have actually used prayer as part of their arthritis treatment. The perception of the helpfulness of prayer may be an important explanatory variable in the relationship between ethnicity and patients' decisions when considering arthroplasty.

Bao, Y., Sturm, R., & Croghan, T. W. (2003). A national study of the effect of chronic pain on the use of health care by depressed persons. *Psychiatric Services, 54,* 693-697.
Refid: 110288
Main message:

- Comorbid pain among persons with depression is associated with more intensive use of general medical services, but lower rates of mental health services usage compared to that of depressed persons with no pain.

Summary: The purpose of this quantitative cross-sectional study was to provide national estimates of the impact of common pain conditions (including self-reported arthritis) on the use of health services and quality of care among persons with depression. The results demonstrated that depressed persons with comorbid pain were older, had lower incomes and reported more severe psychiatric distress than depressed persons who did not have pain. Patients with comorbid pain paid more visits to medical providers, but they were less likely than patients without pain to see a mental health specialist. It was also shown that pain was associated with greater use of complementary or alternative medicine but not with differences in the use of antidepressants.

Blake, V. A., Allegrante, J. P., Robbins, L., Mancuso, C. A., Peterson, M. G., Esdaile, J. M., Paget, S. A., & Charlson, M. E. (2002). Racial differences in social network experience and perceptions of benefit of arthritis treatments among New York City Medicare beneficiaries with self-reported hip and knee pain. *Arthritis & Rheumatism, 47,* 366-371.
Refid: 110493
Main messages:

- The choice of whether or not to have surgery as a treatment option for arthritis appears to vary by race.
- The perception of risk of surgery is much higher among African-Americans compared to Caucasians and is a barrier when considering surgery.

Summary: This quantitative study examined social networks and perceptions of the benefit of arthritis treatments and whether they influenced a decision to seek diagnosis and treatment. The results showed that African-Americans know fewer people who have had surgical treatment of hip and knee pain than Caucasians do and appear to be less likely to perceive such treatment as beneficial.

Carlson, M. J. & Krahn, G. (2006). Use of complementary and alternative medicine practitioners by people with physical disabilities: estimates from a national US survey. *Disability and rehabilitation, 28,* 505-513.
Refid: 110795
Main message:

- In this study sample, 19% of participants with physical disabilities used complementary and alternative medicine (CAM).

Summary: The goals of this survey were to estimate the prevalence of CAM use among people with physical disabilities, to assess the reasons for their use and to determine the symptoms for which CAM practitioners were consulted. CAM use was more prevalent among women than men, in the Western US than in the Midwest and among those patients who had used CAM before compared with those who had not. There were no significant differences by condition in CAM use. In this study, most people reported using CAM to treat pain, decreased functioning and lack of energy. Common reasons for using CAM included

Kim, H. A. & Seo, Y. I. (2003). Use of complementary and alternative medicine by arthritis patients in a university hospital clinic serving rheumatology patients in Korea. *Rheumatology international, 23,* 277-281.
Refid: 112630
Main messages:

- A lower income is associated with more frequent use of CAM in Korea.
- CAM use is rarely discussed with physicians.

Summary: A survey was conducted of patients in rheumatology clinics to assess the use of CAM, related demographic and clinical factors, and attitudes among Korean arthritis patients. At least one form of CAM was used by 68.5% of the respondents during the preceding 12 months. Herbal remedies and acupuncture were the most frequently used categories. Income level was significantly and negatively associated with the frequent or regular use of CAM. Korean patients do not seem to discuss CAM use with their physicians. The main reason offered for not discussing CAM use with physicians was that the patients had "not been asked" by their physicians if they were using CAM.

Lazarus, H. & Neumann, C. J. (2001). Assessing undertreatment of pain: the patients' perspectives. *Journal of Pharmaceutical Care in Pain & Symptom Control, 9,* 5-34.
Refid: 112892
Main message:

- Pain among patients with chronic diseases such as arthritis is undertreated.

Summary: An in-depth qualitative interview survey was conducted with 1,000 persons living at home with pain due to a medical condition to assess their attitudes toward pain, medications and their doctors, as well as to identify the size and scope of undertreatment. Of those interviewed, 90% had seen a physician, 67% were under a doctor's care, 86% saw the same clinician for the pain and its cause, 50% saw a general practitioner or family physician, 13% had seen a pain specialist, 42% said their prescription analgesic was less than very effective, 67% indicated that their daily lives had been altered by pain and 51% said they could not remember what it felt like not to be in pain.

Lee, G. B. W., Charn, T. C., Chew, Z. H., & Ng, T. P. (2004). Complementary and alternative medicine use in patients with chronic diseases in primary care is associated with perceived quality of care and cultural beliefs. *Family practice*, *21*, 654-660.
Refid: 112910
Main message:

- CAM use in Asian patients is prevalent and associated with the 'chronic disease triad' (of arthritis, musculoskeletal disorders and stroke), satisfaction with care and cultural beliefs.

Summary: A cross-sectional study based on a random sample of 488 adult patients with chronic diseases was carried out in Singapore. Factors associated with CAM use included middle age, arthritis, musculoskeletal disorders and stroke, multiple conditions, poor perceived health, family use of CAM, recommendation by close social contacts, strong adherence to traditional health beliefs and perceived satisfaction with care. CAM use was also significantly and independently predicted by the 'chronic disease triad' (arthritis/musculoskeletal disorders/stroke).

Lewis, D., Paterson, M., Beckerman, S., & Sandilands, C. (2001). Attitudes toward integration of complementary and alternative medicine with hospital-based care. *Journal of Alternative and Complementary Medicine, 7,* 681-688.
Refid: 112978
Main message:

- Most respondents, some of whom had arthritis, would accept integration of complementary and alternative techniques into a hospital. Therapies would be more acceptable if there were clear evidence of their efficacy.

Summary: A cross-sectional survey was undertaken to characterize the use of complementary and alternative therapies. The three most common therapies used were chiropractic, massage and herbal/phytology; the three most common reasons for use were general health, fatigue and arthritis. Of those surveyed, 33% would use holistic therapy in the future. Barriers to use were lack of information, perceived ineffectiveness and cost. Approximately 40% agreed they would only use complementary and alternative therapies with medical advice. Approximately 13% were opposed to complementary and alternative therapy and objected to its use in hospitals. Youth, preference for complementary and alternative therapy over conventional medicine, and prior use of these therapies independently predicted high likelihood for future use. A lower income and high self-perceived health were associated with a negative attitude toward the use of holistic therapies in hospital.

Singh, V., Raidoo, D. M., & Harries, C. S. (2004). The prevalence, patterns of usage and people's attitude towards complementary and alternative medicine (CAM) among the Indian

community in Chatsworth, South Africa. *Journal*.
Refid: 114668
Main message:

- The prevalence of CAM in Chatsworth is similar to findings in other parts of the world. This practice could not be attributed to any particular demographic profile.

Summary: Structured interviews were conducted with 200 randomly selected South Africans of Indian origin to explore the use of CAM in this population. It emerged that 38.5% of the participants used CAM to treat conditions including diabetes mellitus, headaches, arthritis and joint pains, stress, skin disorders, backaches, hypertension and nasal disorders. Spiritual healing and herbal/natural medicines, including vitamins, were the most common types of CAM used. Seventy-nine percent of CAM users indicated that they enjoyed positive outcomes with their treatments.

Ware, M. A., Adams, H., & Guy, G. W. (2005). The medicinal use of cannabis in the UK: Results of a nationwide survey. *International journal of clinical practice, 59,* 291-295.
Refid: 115300
Main message:

- In the UK medicinal cannabis is used by up to 55% of people, especially in younger people (both male and female) and older males, with chronic conditions including arthritis.

Summary: A self-administered questionnaire study of 2,969 people in which subjects were self-selected was conducted in the UK. Medicinal cannabis use was reported by patients with chronic pain, multiple sclerosis, depression, arthritis and neuropathy. Medicinal cannabis use was associated with youth, males and previous recreational use. Researchers advised caution on the interpretation of these data because the study population was self-selected rather than randomly selected, which introduces a risk of selection bias in the results. They recommended that further clinical studies were required to target people who have never used or rarely use cannabis in order to determine the effectiveness of cannabis for pain management.

Wold, R. S., Wayne, S. J., Waters, D. L., & Baumgartner, R. N. (2007). Behaviors underlying the use of nonvitamin nonmineral dietary supplements in a healthy elderly cohort. *Journal of Nutrition, Health and Aging, 11,* 3-7.
Refid: 115440
Main message:

- Arthritis was found to be a main reason for using nonvitamin nonmineral dietary supplements (NVNM). While many arthritis sufferers reported improved mobility and less joint pain, over half indicated that they did not feel any benefit from taking supplements yet they continued to use them.

Summary: Questionnaires were administered to 418 people aged 60-69. The results showed that NVNM supplement "consumers" and "non-consumers" were not significantly different for sex, age, ethnicity, perceived health status, income level and health insurance access. Arthritis, memory improvement and general health and well-being were the main reasons for using NVNM supplements. Less joint pain/improved mobility was the main perceived improvement from taking NVNM supplements.

General arthritis: Surgery – qualitative studies (N=3)

Ballantyne, P. J., Hawker, G. A., & Radoeva, D. (2001). The Extended Self: Illness Experiences of Older Married Arthritis Sufferers. *Research in the Sociology of Health Care, 19,* 261-282.
Refid: 110275
Main message:

- The quality of a marital relationship influences the daily functioning of people with arthritis.

Summary: This qualitative study was conducted to assess patients' experiences with arthritis. A discrepancy between the need for treatment and patients' willingness to consider treatment involving TJA emerged. The results suggested that a couple's relationship and functional behaviours influenced the meaning of the disease and health care decision-making for an individual.

Clark, J. P., Hudak, P. L., Hawker, G. A., Coyte, P. C., Mahomed, N. N., Kreder, H. J., & Wright, J. G. (2004). The moving target: a qualitative study of elderly patients' decision-making regarding total joint replacement surgery. *Journal of Bone and Joint Surgery (American), 86A,* 1366-1374.
Refid: 110956
Main message:

- The main factors influencing decision-making about total joint replacement surgery are symptoms and information sources.

Summary: The purpose of this study was to understand elderly patients' unwillingness to undergo total joint replacement surgery by exploring the nature of their decision-making processes. The results showed that participants evaluated the perceived costs and benefits of total joint replacement surgery. A phenomenon called "the moving target" was also discussed. This can be characterized as the process in which the benefits are compared with the risks, finally tilting in favour of total joint replacement.

Radwin,L. E. (2008). Arthritis symptoms, information sources, and a constantly shifting threshold of risk-benefit ratios influenced elderly patients' decisions about total joint replacement., *Evidence-Based Nursing, 8(2),* 63.

Refid: 114092

Main message:

- Commentary on a study about the factors that influence elderly patients' decisions to undergo total joint replacement (TJR), stating that the information is useful to nurses who can tailor their information to the needs of the patient to help better prepare them to make decisions about elective surgery.

Summary: The author reflects on the paper by Clark et al which found that patients do not always fully understand the benefits and risks of proposed treatments. The author posits that nurses can provide educational content that is tailored to the specific patient, which is more useful than standardized educational content. Nurses who "know their patients" can also share experiential knowledge, and are well suited to provide advice about elective treatments based on the patient's values and needs.

General arthritis: Surgery – quantitative studies (N=6)

Ang, D. C., Ibrahim, S. A., Burant, C. J., Siminoff, L. A., & Kwoh, C. K. (2002). Ethnic differences in the perception of prayer and consideration of joint arthroplasty. *Medical care, 40,* 471-476.
Refid: 110160
Main message:

- Patients' perceptions of the benefits of prayer may influence their decisions about surgery.

Summary: This quantitative study examined ethnic differences in the perception and use of prayer in the treatment of arthritis and its role in patients' decision-making about surgery. It aimed to measure the "helpfulness of prayer" in the treatment of arthritis and patients' attitudes toward joint arthroplasty. The results demonstrated that African-American patients were more likely than Caucasian patients to perceive prayer as helpful and that they were more likely to have actually used prayer as part of their arthritis treatment. The perception of the helpfulness of prayer may be an important explanatory variable in the relationship between ethnicity and patients' decisions when considering arthroplasty.

Blake, V. A., Allegrante, J. P., Robbins, L., Mancuso, C. A., Peterson, M. G., Esdaile, J. M., Paget, S. A., & Charlson, M. E. (2002). Racial differences in social network experience and perceptions of benefit of arthritis treatments among New York City Medicare beneficiaries with self-reported hip and knee pain. *Arthritis & Rheumatism, 47,* 366-371.
Refid: 110493
Main messages:

- The choice of whether or not to have surgery as a treatment option for arthritis appears to vary by race.
- The perception of risk of surgery is much higher among African-Americans compared to Caucasians and is a barrier when considering surgery.

Summary: This quantitative study examined social networks and perceptions of the benefit of arthritis treatments and whether they influenced a decision to seek diagnosis and treatment. The results showed that African-Americans know fewer people who have had surgical treatment of hip and knee pain than Caucasians do and appear to be less likely to perceive such treatment as beneficial.

Chipperfield, J. G. & Greenslade, L. (1999). Perceived control as a buffer in the use of health care services. *Journals of Gerontology Series B-Psychological Sciences & Social Sciences, 54,* 146-154.
Refid: 110898
Main message:

- Patients with low levels of perceived control (the ability to influence outcomes and events in the environment) use health services more often than patients with high levels of perceived control.

Summary: The purpose of this study was to examine the link between perceived control and patterns of health service use among older people with arthritis. Individuals who perceived low levels of control were found to use more health services than their high-control counterparts; they visited their physicians more often, had more laboratory tests, and stayed longer in the hospital. This was true only for those who reported being restricted by their arthritis.

Hawker, G. A., Wright, J. G., Glazier, R. H., Coyte, P. C., Harvey, B., Williams, J. I., & Badley, E. M. (2002). The effect of education and income on need and willingness to undergo total joint arthroplasty. *Arthritis & Rheumatism, 46,* 3331-3339.
Refid: 112106
Main message:

- Persons with lower socioeconomic status (SES) had a greater need for arthroplasty, and were equally willing to consider it, compared with those with higher SES. Observed SES disparities in the rates of performed arthroplasties cannot be explained by a lesser need or less willingness to undergo arthroplasty in those with lower SES.

Summary: This survey assessed education, income, arthritis severity and comorbidity in 28,451older individuals with moderate-to-severe hip/knee problems living in Ontario, Canada. In a subset of 2,411 participants, the diagnosis of arthritis was validated and interviews were conducted to evaluate willingness to consider TJA. Less education and lower income were independently associated with a greater likelihood of a potential need for arthroplasty. Among those with a potential need, neither education nor income was independently associated with a definite willingness to consider arthroplasty. Thus, taking willingness into consideration, individuals with less education and/or a lower income were more likely to have a potential unmet need for arthroplasty.

Hawker, G. A., Wright, J. G., Badley, E. M., & Coyte, P. C. (2004). Perceptions of, and willingness to consider, total joint arthroplasty in a population-based cohort of individuals with disabling hip and knee arthritis. *Arthritis & Rheumatism, 51,* 635-641.
Refid: 112107
Main message:

- People with arthritis may overestimate the pain and disability needed to warrant TJA; these misperceptions were strongly associated with unwillingness to consider TJA.

Summary: This survey covered 379 people aged 55 or older with hip or knee arthritis. About 34% reported that they were willing to consider TJA as a treatment option. Willingness was independently associated with the following factors: younger age, perceived higher arthritis severity, perception of TJA as appropriate for controlling joint pain, inability to walk more than one block, perception of an acceptable potential risk of needing additional surgeries and using friends as an important source of health information.

Losina, E., Barrett, J., Baron, J. A., Levy, M., Phillips, C. B., & Katz, J. N. (2004). Utilization of low-volume hospitals for total hip replacement. *Arthritis & Rheumatism, 51,* 836-842.
Refid: 113109
Main message:

- Restricting THR to high-volume centres would differentially affect patients who were poor, less educated and living in rural regions with lower-volume health care centres.

Summary: Multiple data sources including medical record review, Medicare claims data, 1990 Census data and a patient survey were used to examine factors independently associated with the use of low-volume hospitals for elective THR surgery. The results showed that rural residency, low income, and low educational attainment, as well as a belief in the importance of convenient location in the choice of hospital, were associated with a higher use of low-volume hospitals. Rural and suburban patients who went to low-volume hospitals travelled much less than patients operated upon in high-volume centres.

General arthritis: Information – qualitative studies (N=3)

Clark, J. P., Hudak, P. L., Hawker, G. A., Coyte, P. C., Mahomed, N. N., Kreder, H. J., & Wright, J. G. (2004). The moving target: a qualitative study of elderly patients' decision-making regarding total joint replacement surgery. *Journal of Bone and Joint Surgery (American), 86A,* 1366-1374.
Refid: 110956
Main message:

- The main factors influencing decision-making about total joint replacement surgery are symptoms and information sources.

Summary: The purpose of this study was to understand elderly patients' unwillingness to undergo total joint replacement surgery by exploring the nature of their decision-making processes. The results showed that participants evaluated the perceived costs and benefits of total joint replacement surgery. A phenomenon called "the moving target" was also discussed. This can be characterized as the process in which the benefits are compared with the risks, finally tilting in favour of total joint replacement.

Gibbs, L. (2005). Applications of Masculinity Theories in a Chronic Illness Context. *International Journal of Men's Health, 4,* 287-300.
Refid: 111787
Main messages:

- Men’s sense of masculinity may shift when dealing with arthritis.
- When the pain is more severe and their physical limitations are greater, they may be unable to work, socialize or maintain their role in relation to their partners and friends.

Summary: The objective of this qualitative study was to explore men's experience with arthritis and to identify influences on men's decisions to participate in arthritis self-management programs. One of the themes that emerged was that men's sense of their own masculinity appeared to shift in response to the impact of arthritis so that they tended to avoid self-management programs that would allow them to talk about their feelings.

Hale,E. D., Treharne,G. J. Lyons,A. C., Norton,Y., Mole,S., Mitton,D. L., Douglas,K. M., Erb,N., Kitas,G. D. (2005). "Joining the dots" for patients with systemic lupus erythematosus: personal perspectives of health care from a qualitative study. *Annals of the Rheumatic Diseases, 65(5),* 585 – 589.
Refid: 141135
Main Message:

- Patients living with systemic lupus erythematosus (SLE) in the United Kingdom do not feel that their condition is well-understood by all if their health care providers or people close to them. Increased communication between various health professionals and readily available information about SLE may help to minimize patients’ feelings of isolation.

Summary: Semi-structured interviews were conducted with 10 women aged 26 to 68 years who were diagnosed with SLE 1 to 12 years earlier. Four themes emerged: diagnostic difficulties; understanding; communication; and integrated health care. Before diagnosis there was concern to appear legitimately ill and to have a label for the condition. After diagnosis participants still encountered health care professionals who were poorly informed about SLE. Family, friends, and employers did not understand the fluctuating nature of SLE, which often led to isolation. Participants felt that even health care professionals who specialized in SLE could not fully understand the psychosocial impact of the condition, and therefore did not provide information to meet those needs. Participants did not know which of the many health care professionals they had contact with to approach about their concerns. Lack of communication at an interdisciplinary level left them feeling that nobody was "joining the dots" for their health care.

General arthritis: Information – quantitative studies (N=10)

Dubbert, M. L., Sharp, G. C., Kay, D. R., Sylvester, J. L., & Brownson, R. C. (1990). Implications of a statewide survey of arthritis in Missouri. *Missouri medicine, 87,* 145-148.
Refid: 111342
Main message:

- The majority of patients with arthritis who were surveyed in this study were misinformed and lacked knowledge about their condition. Television, newspapers and magazines were identified as the most popular sources of information about arthritis.

Summary: This study involved a random sample of 2,533 households contacted by phone for a survey about their knowledge of arthritis. The response rate was 68% and approximately one out of four respondents had arthritis. The majority of participants did not know the difference between the common types of arthritis, their causes and their treatments. They also felt that a person should only seek help when their symptoms were severe. The media was identified as the most effective way to obtain information about the disease.

Gordon, M. M., Capell, H. A., & Madhok, R. (2002). The use of the Internet as a resource for health information among patients attending a rheumatology clinic. *Rheumatology, 41,* 1402-1405.
Refid: 111868
Main message:

- The use of the Internet for researching health information is common among people with arthritis. One in four patients attending a rheumatology clinic had searched the Internet for medical information in the preceding 12 months, and almost one-third found it easier than asking their health care professional.

Summary: This questionnaire-based study aimed to determine the proportion of patients attending a rheumatology clinic with Internet access, and to assess how often they searched for health information and how useful they found the information. Of 138 people who completed the questionnaires, 78% had RA. Patients searched online for information about arthritis, drug treatment, alternative therapies, diet and patient organizations. None of the participants recalled being advised to search for information by their doctors or nurses. Patients who searched for medical information were younger, more likely to be employed and more likely to be married or in a stable relationship; there were no differences in sex distribution, diagnosis, disease duration or social deprivation.

Kim, H. A., Bae, Y. D., & Seo, Y. I. (2004). Arthritis information on the Web and its influence on patients and physicians: a Korean study. *Clinical & Experimental Rheumatology, 22,* 49-54.
Refid: 112628
Main message:

- An analysis of Korean arthritis websites revealed many sites with financial interests and a discrepancy between patients and physicians regarding the impact of Web-sourced arthritis information on the doctor-patient relationship.

Summary: Questionnaire surveys of patients with arthritis and rheumatologists were performed to appraise the impact of arthritis information available on the Web. Among 257 patients surveyed, 28% reported that they searched for arthritis information on the Web. Factors associated with using the Web for arthritis information were youth, employment and having a higher income and higher level of education. While the difference in ratings regarding the accuracy of Web-sourced arthritis information between physicians and patients was not significant, only about 16% of physicians responded that their patients understood the Internet content accurately. Physicians also tended to reply more negatively than patients about the content and the influence of Web-sourced arthritis information.

Kjeken, I., Dagfinrud, H., Mowinckel, P., Uhlig, T., Kvien, T. K., & Finset, A. (2006). Rheumatology care: Involvement in medical decisions, received information, satisfaction with care, and unmet health care needs in patients with rheumatoid arthritis and ankylosing spondylitis. *Arthritis & Rheumatism, 55,* 394-401.
Refid: 124337
Main message:

- There is a need for a more flexible and patient-centred care model in which patients with RA or ankylosing spondylitis can decide which services they need and how they should be delivered.

Summary: Questionnaires were completed by 1,193 patients with RA and ankylosing spondylitis. The majority of patients reported medium to high levels of information received about RA, involvement in medical decisions and satisfaction with care. High involvement in medical decisions was associated with high levels of perceived information and satisfaction, as well as with lower age and a good health status. Patient satisfaction, a high level of received information, age and 12+ years of formal education were significant predictors to current involvement. Nearly one-third of the respondents reported a variety of unmet health care needs, and this report was associated with poor health.

Maisiak, R., Koplon, S., & Heck, L., Jr. (1989). Users of a public arthritis information service and their needs. *Journal of Rheumatology, 16,* 1474-1479.
Refid: 113194
Main message:

- Telephone services for health promotion should make special efforts to reach non-Caucasian and less educated persons, and to provide emotional support to people with arthritis.

Summary: Brief interviews were conducted with 1,670 users of the Arthritis Information Service of Alabama, a statewide toll-free telephone information service. The results showed that service users tended to be female, white and older; to have arthritis symptoms; and to be better educated than the general adult population. The most frequent category of need was emotional support, followed by information about referrals, symptoms, tests, self-help methods and medications, and ways to improve physician-patient communication. Informational needs were significantly related to the sex, age and reported diagnoses of the user.

Maisiak, R., Koplon, S., & Heck, L. W. (1990). Subsequent behavior of users of an arthritis information telephone service. *Arthritis & Rheumatism, 33,* 212-218.
Refid: 113197
Main message:

- The use of telephone information services may increase subsequent positive actions taken and the sense of control in people with arthritis.

Summary: Follow-up telephone interviews were conducted with a random sample of 305 users of a prototype telephone information service for arthritis two to four months after their initial contact with the service. Of those surveyed, 79% reported taking at least one positive action for their arthritis because of service usage. The most frequently reported actions were asking the doctor more questions and greater compliance with the doctor's orders. About half of the respondents felt more in control of their arthritis because of service usage. Respondents who were younger than 60 years old, black or symptomatic were significantly more likely to take an action. This minimal intervention may stimulate positive behaviours for individuals with arthritis.

Mauksch, L. B., Katon, W. J., Russo, J., Tucker, S. M., Walker, E., & Cameron, J. (2003). The content of a low-income, uninsured primary care population: Including the patient agenda. *Journal of the American Board of Family Practice, 16,* 278-289.
Refid: 113316
Main message:

- A survey of primary care clinic patients in an uninsured, low-income population of Colorado showed that their health issues consisted mostly of physical pain and emotional distress. These needs place a serious burden on providers and can complicate the management of patients' chronic medical illnesses.

Summary: A survey was conducted with 500 consecutive patients in a primary care clinic serving only uninsured, low-income patients. Participants reported that their most common chronic medical problems were headaches, chronic back problems and arthritis. The most common concerns patients wanted to discuss with health care providers were emotional issues. When compared with patients without mental illness, those with a current major mental illness reported significantly more concerns about their health, physical symptoms, chronic illnesses, stressors and higher incidences of abuse during their life.

Millard, R. W. & Fintak, P. A. (2002). Use of the internet by patients with chronic illness. *Disease Management and Health Outcomes, 10,* 187-194.
Refid: 113449
Main message:

- A growing number of activist health consumers are using the Internet to help manage their health. These individuals are more likely to be female, in poorer health and more inclined to engage in self-care, and may lack access to professional care.

Summary: An online survey was conducted among 10,069 patients with chronic illnesses. The most frequently reported conditions were allergies, arthritis and hypertension. Respondents who complained of a gynecological condition, chronic sinusitis, arthritis, migraine or a thyroid condition reported spending the most time online. Those who were more skeptical about healthcare, or were dissatisfied or experienced problems with access to healthcare, reported being more likely to go to the Internet as a source of health information. The Internet appeared to be used as a surrogate for medical advice among patients who lack insurance coverage or otherwise find it difficult to obtain care.

Horton,R. Peterson,M. G. Powell,S. Engelhard,E. Paget,S. A. (1997) Users evaluate LupusLine, a telephone peer counseling service. *Arthritis Care & Research, 10(4),* 257 – 263.
Refid: 141259
Main Message:

- Telephone networks similar to the LupusLine model may be able to offer substantial benefit to people coping with the complex, ongoing psychosocial challenges of SLE. The at-home accessibility and low cost of such volunteer-based interventions may play an ever more needed role in the present health care environment.

Summary: A survey was conducted to assess the impact of LupusLine during its pilot phase of operation by determining patterns of utilization and user satisfaction. LupusLine is a peer counseling service designed to provide ongoing emotional support from home to home by telephone appointment. One hundred fifty-three respondents completed a structured questionnaire administered over the telephone. Most users were women (94.5%) who had SLE themselves (87.5%) and who called the service because of recent changes in their physical functioning and reported feelings of depression and anxiety about their illness. Forty-one percent of respondents made 6 or more calls to their assigned peer counselor. Respondents reported high levels of satisfaction across 5 highly correlated measures, with 92% of callers reporting at least moderate satisfaction with the service. Over 60% of respondents who reported a change in 6 "feeling" categories attributed this change to using LupusLine. Fewer users reported a change in 4 specific behaviors since using the service, but more respondents attributed changes, when they occurred, to LupusLine.

Shuyler, K. S. & Knight, K. M. (2003). What are patients seeking when they turn to the internet? Qualitative content analysis of questions asked by visitors to an orthopaedics web site. *Journal of Medical Internet Research, 5,* 1-22.
Refid: 114619
Main message:

- People with arthritis look for online information about their condition, treatments and symptoms, and for advice about their symptoms and treatments.

Summary: This study analyzed queries submitted to an orthopedic website by people with arthritis from 34 nations, including Canada, the United States, Australia and the UK, and identified the top five reasons for using the website: (1.) seeking information about a condition, (2.) seeking information about treatment, (3.) seeking information about symptoms, (4.) obtaining advice about symptoms, and (5.) obtaining advice about treatment.

Other: Diagnosis – qualitative studies (N=1)

Painful thumb

Candib, L. M. (2004). Making sense of my thumbs: Coming to terms with chronic illness. *Families, Systems and Health, 22,* 139-151.

Refid: 110777

Main message:

- Patients first need to accept and make sense of their illness, and then they can start making life changes to manage it.

Summary: This narrative described a patient's search for a diagnosis and treatment of pain in her thumbs. The conventional diagnostic process was not enough for her. However, using the holistic approach of complementary health care, including massage therapy and acupuncture, combined with physical therapy, gave the patient a sense of empowerment over her arthritis. As the patient wrote about the experience, she recognized that she had been having difficulty accepting the aging process and having a chronic illness. Writing about her arthritis helped her accept her disease and it showed her the ways in which she had changed during the process.

Other

Diagnosis – quantitative studies (N=0)

Other: Medication – qualitative studies (N=3)

Juvenile arthritis, treatment seeking

Barlow, J. H., Shaw, K. L., & Harrison, K. (1999). Consulting the 'experts': Children's and parents' perceptions of psycho-educational interventions in the context of juvenile chronic arthritis. *Health education research, 14,* 597-610.

Refid: 110303

Main message:

- Children with juvenile chronic arthritis and their parents want greater availability of and easier access to information about the disease, and more comprehensive educational interventions.

Summary: This qualitative study used focus group interviews to examine the needs and preferences of both children with juvenile chronic arthritis (JCA) and their parents, and also to look at how their needs may be addressed through educational interventions. The results showed that both children and parents believed that current interventions were inappropriate. Parents expressed frustration and anger at social barriers in their attempts to achieve a sense of normalcy. The greatest concern among children was peer belonging and social acceptance.

Upper limb pain

Calnan, M. W., Wainwright, D., O'Neill, C., Winterbottom, A., & Watkins, C. (2006). Making sense of aches and pains. *Family practice, 23,* 91-105.

Refid: 110766

Main messages:

- The most common strategy for people with upper limb pain is to wait and see what happens.
- Orthodox practitioners are generally used first by patients with limb pain for formal care.

Summary: This qualitative study presented evidence about how sufferers with upper limb disorders respond to their pain. The interviews with patients involved discussions about how their pain was managed, when and to whom they went for formal help and how they evaluated the care they received. The results showed that most patients would wait and see what happened, and that pain was believed to be a natural part of aging. Most patients used self-management strategies but orthodox practitioners were usually the first choice for formal care. Complementary and alternative medicines (CAM) were popular but were used to complement orthodox care.

Upper limb pain

Calnan,M., Wainwright,D., O'Neill,C., Winterbottom,A., Watkins,C. (2007). Illness action rediscovered: a case study of upper limb pain. *Sociology of health & illness, 29,* 321-346.
Refid: 170001
Main message:

- The use of both orthodox and non-orthodox care formed part of the strategies used to manage upper limb pain.

Summary: Case studies were presented about patients with upper limb pain and how they acted on their illness. The results identified the complex process of help-seeking and showed that the use of both orthodox and non-orthodox care formed only part of the strategies used to manage upper limb pain. The other part of the strategies used by patients included evaluation of the care they received in terms of pain alleviation. Patients were resigned to searching for the best way of living with their pain.

Other: Medication – quantitative studies (N=1)

Knee pain

Mitchell,H. L. Carr,A. J. Scott,D. L. (2006). The management of knee pain in primary care: factors associated with consulting the GP and referrals to secondary care. *Rheumatology, 45(6),* 771 – 776.
Refid: 134345

Main message:

- Questionnaires sent to people in southeast London, UK identified those with knee pain in order to find out how disability, severity of the condition, and health beliefs relate to consultation rates and referrals to specialist services. It was found that people who consulted their GP about their knee pain tended to have more severe disease and higher levels of disability, and believed that their condition had major consequences on their lives.

Summary: Individuals with knee pain were identified through questionnaires sent to patients aged 50 and older from 2 GP practices in southeast London. Of the 2940 questionnaires sent out, 34% were completed; of these, 49% reported having knee pain within the last 12 months and were invited to the department, and 231 people (47%) chose to participate. Of those who participated, 31% were given a diagnosis of OA. Factors that predict GP consultation are the perceived disease impact, the belief that the knee pain would have permanent effects, and that it would influence how others saw them. Factors that predict referral to specialists are knee swelling, the perceived disease impact, the belief that the knee pain would have permanent effects, and that it would influence how others saw them.

Other: Allied health – qualitative studies (N=3)

Upper limb pain

Calnan, M. W., Wainwright, D., O'Neill, C., Winterbottom, A., & Watkins, C. (2006). Making sense of aches and pains. *Family practice, 23,* 91-105.

Refid: 110766

Main messages:

- The most common strategy for people with upper limb pain is to wait and see what happens.
- Orthodox practitioners are generally used first by patients with limb pain for formal care.

Summary: This qualitative study presented evidence about how sufferers with upper limb disorders respond to their pain. The interviews with patients involved discussions about how their pain was managed, when and to whom they went for formal help and how they evaluated the care they received. The results showed that most patients would wait and see what happened, and that pain was believed to be a natural part of aging. Most patients used self-management strategies but orthodox practitioners were usually the first choice for formal care. Complementary and alternative medicines (CAM) were popular but were used to complement orthodox care.

Upper limb pain

Calnan,M., Wainwright,D., O'Neill,C., Winterbottom,A., Watkins,C. (2007). Illness action rediscovered: a case study of upper limb pain. *Sociology of health & illness, 29,* 321-346.

Refid: 170001

Main message:

- The use of both orthodox and non-orthodox care formed part of the strategies used to manage upper limb pain.

Summary: Case studies were presented about patients with upper limb pain and how they acted on their illness. The results identified the complex process of help-seeking and showed that the use of both orthodox and non-orthodox care formed only part of the strategies used to manage upper limb pain. The other part of the strategies used by patients included evaluation of the care they received in terms of pain alleviation. Patients were resigned to searching for the best way of living with their pain.

Painful thumb

Candib, L. M. (2004). Making sense of my thumbs: Coming to terms with chronic illness. *Families, Systems and Health, 22,* 139-151.

Refid: 110777

Main message:

- Patients first need to accept and make sense of their illness, and then they can start making life changes to manage it.

Summary: This narrative described a patient's search for a diagnosis and treatment of pain in her thumbs. The conventional diagnostic process was not enough for her. However, using the holistic approach of complementary health care, including massage therapy and acupuncture, combined with physical therapy, gave the patient a sense of empowerment over her arthritis. As the patient wrote about the experience, she recognized that she had been having difficulty accepting the aging process and having a chronic illness. Writing about her arthritis helped her accept her disease and it showed her the ways in which she had changed during the process.

Other: Allied health – quantitative studies (N=1)

Knee pain

Mitchell,H. L. Carr,A. J. Scott,D. L. (2006). The management of knee pain in primary care: factors associated with consulting the GP and referrals to secondary care. *Rheumatology, 45(6),* 771 – 776.
Refid: 134345

Main message:

- Questionnaires sent to people in southeast London, UK identified those with knee pain in order to find out how disability, severity of the condition, and health beliefs relate to consultation rates and referrals to specialist services. It was found that people who consulted their GP about their knee pain tended to have more severe disease and higher levels of disability, and believed that their condition had major consequences on their lives.

Summary: Individuals with knee pain were identified through questionnaires sent to patients aged 50 and older from 2 GP practices in southeast London. Of the 2940 questionnaires sent out, 34% were completed; of these, 49% reported having knee pain within the last 12 months and were invited to the department, and 231 people (47%) chose to participate. Of those who participated, 31% were given a diagnosis of OA. Factors that predict GP consultation are the perceived disease impact, the belief that the knee pain would have permanent effects, and that it would influence how others saw them. Factors that predict referral to specialists are knee swelling, the perceived disease impact, the belief that the knee pain would have permanent effects, and that it would influence how others saw them.

Other: CAT – qualitative studies (N=3)

Upper limb pain

Calnan, M. W., Wainwright, D., O'Neill, C., Winterbottom, A., & Watkins, C. (2006). Making sense of aches and pains. *Family practice, 23,* 91-105.
Refid: 110766

Main messages:

- The most common strategy for people with upper limb pain is to wait and see what happens.
- Orthodox practitioners are generally used first by patients with limb pain for formal care.

Summary: This qualitative study presented evidence about how sufferers with upper limb disorders respond to their pain. The interviews with patients involved discussions about how their pain was managed, when and to whom they went for formal help and how they evaluated the care they received. The results showed that most patients would wait and see what happened, and that pain was believed to be a natural part of aging. Most patients used self-management strategies but orthodox practitioners were usually the first choice for formal care. Complementary and alternative medicines (CAM) were popular but were used to complement orthodox care.

Upper limb pain

Calnan,M., Wainwright,D., O'Neill,C., Winterbottom,A., Watkins,C. (2007). Illness action rediscovered: a case study of upper limb pain. *Sociology of health & illness, 29,* 321-346.
Refid: 170001
Main message:

- The use of both orthodox and non-orthodox care formed part of the strategies used to manage upper limb pain.

Summary: Case studies were presented about patients with upper limb pain and how they acted on their illness. The results identified the complex process of help-seeking and showed that the use of both orthodox and non-orthodox care formed only part of the strategies used to manage upper limb pain. The other part of the strategies used by patients included evaluation of the care they received in terms of pain alleviation. Patients were resigned to searching for the best way of living with their pain.

Painful thumb

Candib, L. M. (2004). Making sense of my thumbs: Coming to terms with chronic illness. *Families, Systems and Health, 22,* 139-151.
Refid: 110777
Main message:

- Patients first need to accept and make sense of their illness, and then they can start making life changes to manage it.

Summary: This narrative described a patient's search for a diagnosis and treatment of pain in her thumbs. The conventional diagnostic process was not enough for her. However, using the holistic approach of complementary health care, including massage therapy and acupuncture, combined with physical therapy, gave the patient a sense of empowerment over her arthritis. As the patient wrote about the experience, she recognized that she had been having difficulty accepting the aging process and having a chronic illness. Writing about her arthritis helped her accept her disease and it showed her the ways in which she had changed during the process.

Other: CAT – quantitative studies (N=1)

Juvenile idiopathic arthritis

Feldman, D. E., Duffy, C., De Civita, M., Malleson, P., Philibert, L., Gibbon, M., Ortiz-Alvarez, O., & Dobkin, P. L. (2004). Factors Associated With the Use of Complementary and Alternative Medicine in Juvenile Idiopathic Arthritis. *Arthritis & Rheumatism: Arthritis Care & Research, 51,* 527-532.
Refid: 111538
Main messages:

- Complementary and alternative medicine (CAM) use is not related to poor adherence to conventional medical treatment.
- Adherence to conventional treatment is high for both users and non-users of CAM.

Summary: The purpose of this study was to describe the frequency of and associated factors of CAM use in patients with juvenile idiopathic arthritis (JIA). A total of 118 children participated in the study. Use of CAM was higher in patients whose parents used CAM and among those who considered themselves as being "Canadian" as opposed to belonging to a specific ethnic group.