



Consumer Report from the American College of Rheumatology Annual Scientific Meeting 2003

Introduction

Arthritis Consumer Experts (www.arthritisconsumerexperts.org) focuses on the delivery of research-based education and research participation training for Canadians with arthritis. The Arthritis Research Centre of Canada (www.arthritisresearch.ca) conducts practical research for everyday living. In 2003, both organizations created a “consumer scholarship” which would enable a person living with arthritis from their respective organizations to attend this year’s ACR meeting.

Attending the world’s largest scientific conference on arthritis is a daunting task. Even the most experienced conference attendee gets weary after the first one or two days. Racing back and forth, down long conference centre hallways whilst carrying a mountain of material in one’s hands is neither easy nor enjoyable. This is especially true if you are a person living with arthritis.

In the following report, you will read about the experience and knowledge gained at this year’s American College of Rheumatology Annual Scientific Meeting in the words of three people living with arthritis. Each person chose which presentations they would attend, and before the meeting, they exchanged schedules to ensure that they were covering as much “scientific ground” as possible.

Scholarship awardees were Pam Montie and Pat Quon.

Pam Montie is a Vancouver-based arthritis consumer who attended the ACR conference for her first time. Pam is an Arthritis Consumer Experts’ advisory board member, a member of the Arthritis Research Centre of Canada’s Consumer Advisory Board and a Patient Partner in Arthritis®. Her attendance at the conference was made possible through a scholarship provided by Arthritis Consumer Experts.

Pat Quon, also from Vancouver and living with arthritis, is a member of the Arthritis Research Centre of Canada’s Consumer Advisory Board. Pat’s attendance was supported through a scholarship from the Arthritis Research Centre of Canada. This was Pat’s first ever scientific meeting.

Cheryl Koehn, in her role as president of Arthritis Consumer Experts, attended the meeting for the fifth consecutive year. She provided meeting “mentorship” to Pam and Pat by conducting a review of the meeting program, conference hall logistics, and time and health management strategies, among other issues.

Arthritis Consumer Experts and the Arthritis Research Centre of Canada extends their sincere thanks to Pam and Pat for giving so generously of their volunteer time and health in order to attend the meeting and report to fellow Canadians living with arthritis.

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Please note that all speakers identified in this report are either medical doctors, academic researchers and scientists, or allied health professionals (for example, a physiotherapist or nurse). The speakers did not review or approve the writer's impressions or interpretations of their work.

My ACR “highlights”, by Pam Montie

In attending the ACR Conference, I learned much, met some very interesting people from around the world and made some valuable contacts. I went to many lectures but some were definitely highlights, which I share with you below:

1. How to Assist the Person with Arthritis Considering Self-Employment: Planning for a Winning Strategy

“Practical Advice for People with Arthritis on Starting a Business, From Those Who Have Been There” Presented by Paul Adam

Self-employment may be for good for someone with arthritis for several reasons:

- Flexibility;
- Feeling good about yourself;
- Security of self-employment; and
- The social aspects.

Some negatives of self-employment are:

- Financial insecurity;
- Hard work;
- Not as flexible as expected; and
- Isolation/lack of privacy.

Is self-employment right for me? Things to ask yourself before starting are:

- The financial implications;
- The true meaning of self-employment;
- Do you have the personality and motivation; and
- Awareness of your disease.

To know the type of business to start several things should be considered: your passions, skills, the marketplace, and your disease.

To improve ones chance for success:

- Look for support from family and friends, as well as the business world and other professional services;
- Pace yourself;
- Live a healthy life;
- Maintain a good attitude;
- Plan the business and finances;
- Maintain determination;
- Improve your business skills;
- Organize your work and your work space, setting up your physical environment that works for you; and
- Choose your customers.

“Work Loss from Inflammatory Arthritis: New Insights Gained from Understanding the Patient’s Perspective”
Presented by Diane Lacaille

Most literature emphasizes pain and physical limitations as important causes of work disability. However, working patients ranked fatigue highest in limiting their ability to work. Fatigue reduced energy to perform tasks and interfered with mental abilities as well as with interpersonal relationships with co-workers and clients. Despite its importance with patients, fatigue was the symptom least helped by medications and most difficult to self-manage.

Other arthritis problems identified at work included:

- “Non-visual” nature of the disability;
- Variability of symptom severity, and thus task performance from day to day;
- Unpredictability of flares making it difficult to meet commitments;
- Interpersonal relationships;
- Reluctance to disclose the presence or extent of the RA causing a barrier to workplace support;
- Concern that supports could be perceived as preferential treatment causing resentment;
- Lack of knowledge of existing resources;
- Concern about cost; and
- Emotional barriers to accepting help.

In conclusion, these issues are important to employed people with arthritis. Strategies at work will need to address fatigue and to take into consideration the complexity of interpersonal relationships, the fear of disclosure and the other barriers to using supports.

2. Arthritis Self-Management: From Small Groups to the Internet (ARHP), presented by Kate Lorig

Self-management is defined as 'the patient is an active participant in treatment'. There are three self-management tasks; medical management, role management, and emotional management.

There are also six self-management skills:

- Problem solving;
- Decision making;
- Resource utilization;
- Formation of a patient-provider partnership;
- Action planning; and
- Self-tailoring.

The ASMP (Arthritis Self-Management Program) is proactive patient education to help people live better lives with arthritis. With this focus, the patient is better able to be in charge of his or her disease instead of the doctors, which leads to greater patient satisfaction. The benefit is to help maintain a quality of life where symptoms lessen resulting in a decline in healthcare costs.

Self-efficacy theory is: when someone has a belief that they "can do" - then they "do". Alternatively, if they believe they cannot - then they cannot. This can be changed through:

- Skills mastery – making action plans. Starting at one's own level, doing what you like to do and can do this week.
- Modeling – people seeing others like themselves, both the leaders as well as the others in the class. And, class modeling for each other, patient learning from patient.
- Getting people to think about symptoms in different ways
- Social persuasion – group discussion is better than one-to-one.

In going on the internet, ASMP is attempting to duplicate the course on-line. Expectation at this time is that this is probably two years away from the public. This is being studied at Stanford University with 25 people and two moderators. The moderators (leaders) check everyday through email to encourage and set an example with the participants. There are four parts to the computer software for the participants;

- Learning center – educational center where the participant can learn about the different parts of the program. It is set up so they can see, read or listen. To reach as many people as possible, it is designed so that even a low-tech computer will be compatible;

- Action plan and feedback – there are discussion topics, one or two a week posted to the discussion center, like a bulletin board, not downloadable. All the class has access to this. It is a thread to each other in order to discuss everyone's problems and ideas.
- My stuff – personal items only available to the individual. These would include things like exercise diary, pain diary, and list of medications.
- Help – relaxation tapes, emailing the moderator (moderators logon everyday to check), and a basic computer tutorial (“computers 101”).

An abstract on this has been published for a masters thesis. Information is available at: <http://patienteducation.stanford.edu> which will link to study sites plus all major publications. This is available in Spanish and English.

3. Tai Chi

This session was a brief lesson in Tai Chi. I found it was very beneficial for range of motion, balance and stretching—and it was fun too. There is a video available at www.taichiforarthritis.com. I also found an excellent article on Tai Chi in “Arthritis Self-Management” Magazine, November/December 2003 issue. This is published bi-monthly by R.A. Rapaport Publishing, Inc., 150 West 22nd Street, New York, NY, USA 10011. Canadian subscriptions are \$30 per year (Canadian funds). I received two complimentary issues of this magazine at the conference and found it contained a lot of very relevant information for people with arthritis.

4. Patient Perspective in Outcomes Research: Measuring Fatigue and Other Patient-centered Outcomes in RA

Fatigue is one of the most common symptoms of RA affecting over 80% of patients. It has been identified as a “most problematic” aspect of the disease contributing to an inability to work, recreate and participate in rehabilitation programs. Despite prevalence of fatigue in RA patients, it is rarely assessed in trials, not included in outcome measures, not assessed routinely in clinical settings, and not a primary focus of RA therapy.

“Fatigue: Who Isn’t?”
Presented by Basia Belza

“That which we see the most, we know the least.”

Why measure fatigue?

- Understand the relationship of fatigue with other symptoms such as pain and depression
- Monitor its natural history over time
- Screen or classify individuals with fatigue
- Is a component of health status
- Distinguish between disease conditions
- Guide management decisions
- Evaluate magnitude of change due to treatment

What treatment strategies work to manage fatigue?

- Increase physical activity
- Optimal control of inflammation
- Cognitive behavioral therapy including effective coping strategies
- Self-efficacy enhancing strategies such as symptom reinterpretation

Several studies about fatigue that have been published in the past five years in rheumatic diseases were critiqued with a focus on measurement. Many of these studies used different measurement scales. The highlights of the studies to date are:

- Fatigue, crosses types of rheumatic disease, is serious and highly prevalent;
- Study designs have mostly been descriptive using convenience samples;
- Majority of studies employ self-report measures of fatigue: many scales are not multi-dimensional; and
- Fatigue correlates are: depression, disease, pain, anxiety, feeling of well-being, function, inactivity, and sleep.

From this came some general recommendations: would like to organize an invitational national conference to develop and prioritize directions for research agenda including the patient perspective and support studies in this field, examine variations in fatigue across types and severity of disease condition, age, ethnicity and gender, encourage funding agencies to create targeted grant opportunities, and develop a standardized objective multi-dimensional measurement for fatigue taking into consideration the measurement times to enable capture of variations across time (different times of the day and days of the week).

“The Validity of Patient Centered Outcome Assessment Instruments in RA”

Presented by Patti Katz

Definition of outcomes is the representative effect of health care on the health of the individual. These are mostly measures assessed by the physician and are quantitative (e.g. joint counts, blood work, x-rays, mortality). All these are patient passive and what we should be assessing is the measurement where patients are active reporters. This is called health status of the patient and is defined as the status of the physical – function, disability, psychological well-being, social function, and quality of life. This is a much more patient focused approach. An interesting and important finding from this is that the patient’s report on quality of life and function do not necessarily correlate to the physician’s report.

In summary, patients are important reporters of their health status. Relevant self-reporting outcome measures are available to rheumatologists, some are RA specific, and most are not. Take note that few physicians take individualized patient valuation into account when assessing the patient – this should change.

“Outcomes of Importance, Identified by Patient Focus Groups”

Presented by Monica Ahlmen

The objective of this study was to identify important outcomes reported by RA patients thus improving treatment scheduling and contributing to development of valid outcome measures incorporating patient perspectives. Researchers of this study decided the topics for the interactive discussions. These questions (and answers) for the focus groups included:

- What outcomes from your treatments are important to you? (regaining health, relief of pain, less fatigue, and increase in mobility);
- How do you decide that a treatment is working? (now can manage daily activities and an increase in well-being); and
- What makes you satisfied or dissatisfied with a treatment? (cooperation and communication with health professionals, own responsibility to “take charge”, and resources and access to health care).

From this some areas of future work were identified.

- Have we got access to a valid and reliable measure of fatigue?
- Definition and improvement of well-being?
- Cultural differences between the most important outcomes identified by RA patients?

“What Does Fatigue Mean to Patients With RA?” **Presented by Sarah Hewlett**

Fatigue is a common symptom that patients with RA live with everyday and are told is part of the disease and do not worry about it. In describing fatigue, several areas are addressed.

- Physical problem – patients feel weary, exhausted, like a weight or burden, and wiped out. On the other hand, like wading through mud, sometimes cannot bother with anything, lack of drive or enthusiasm. This is especially devastating in early RA. Another problem is the feeling of being ignored because it is not examinable as the physician cannot “touch” or “feel” fatigue.
- Cause - from the patient’s perspective, is that more energy is required to do tasks causing one to be more tired. Alternatively, that more energy is taken by the body to fight the disease and then nothing is left for them. Is there a link between fatigue and aging?
- Sleep – patients wake up un-refreshed even after nine to 10 hours of sleep. This may be caused by disturbed sleep due to pain, lack of comfort, or inability to turn over without waking up first. Do pain or flares trigger fatigue or maybe they just overdid the previous day?
- Consequences – patients find everything is such an effort. They cannot do everything to the end of the day as they used to. Even leisure and social events are difficult and sometimes have to go home early from a social event because of tiredness. Even family roles have to be adjusted.
- Self-management – Patients have to pace and plan events, learn to ‘read’ their body. Or, the other option is to do everything they want to all at once and suffer with pain and fatigue later.
- Medication treatment – patients find that when the arthritis is under control with medication, both the pain and fatigue decrease.

Fatigue is an important problem that needs more research. It is frequent and persistent and is rarely brought up to the physician by the patient and if it is, it is usually dismissed. This study in the United Kingdom is attempting to devise a standard measure scale for fatigue for the use of physicians and would like it to be included on the core measurement sets used by most rheumatologists.

At the end of this part of the presentation, a discussion arose with the audience. If patients are involved in research from the inception then it is important also to have these research results disseminated to the arthritis community and focus organizations. In addition, patients should be part of the interpretation team, since patients give very different interpretations of the results. It was also suggested that patients should be at least 50% of the interpretation team.

Biologics and Fatigue in the Treatment of RA **Presented by Susan Yount**

With the advance in biologic therapy in the treatment of RA, the study was to examine the effects of various doses and dosing schedules on patient reported fatigue.

The conclusions of the study were that one of the benefits of anti-TNF monoclonal antibody is significant reduction in patient-reported fatigue, that fatigue is rarely assessed in randomized controlled trials or clinical practice and stressing the importance of fatigue prevalence and priority ranking by patients.

I found attending the ACR Annual Scientific Meeting a very rewarding experience. There is so much to learn. I feel I have just scratched the surface. What I came away with was a feeling that we need more patient-oriented subjects at these conferences; we need to get more consumers involved at the research level to promote our ideas and interests from a consumer's perspective for research or to assist the researchers with every level of their work, and we also, and most importantly, need to keep each other informed, educated and advocating for consumer issues. These are not easy tasks. Are you up to the challenge to help make changes in our world? Wouldn't it be beneficial to us all if more patients/consumers could attend these conferences? **Pam Montie**

Scientific "Overload", by Pat Quon

The purpose of my attendance at the ACR meeting was to represent the Arthritis Research Center of Canada's Consumer Advisory Board and to gain further information and insight into the current understanding and treatment of rheumatologic (arthritis) disease. It was the first scientific meeting that I have attended and the first word that I can think of to best describe the experience is simply, "overload".

The meeting attracted nearly 10,000 scientists, rheumatologists and allied health professionals from around the world. It began on Thursday, October 23, 2003 and ran over a four-day period. The first day was considered a pre-conference day focusing primarily on basic research. The Friday consisted of an opening lecture, a few study groups, and then ending in a dessert reception in the evening. The "meat and potatoes" of the meeting began on Saturday, October 25, 2003.

Each day of the meeting consisted of several different categories of lectures that one was able to attend. These categories included lectures which focused specifically on immunology, practice issues, clinical symposia, workshops and original research presentations to name a few. Within each category, there could be anywhere from one to 20 different lectures or presentations occurring simultaneously. Thus, it was quite a task deciding which of the myriad of presentations I should attend at any given time.

Following is my attempt to provide a basic summary of a few of the lectures that I attended.

1. Alternative Medicine: What Do We Know About Its Efficacy and Safety?, presented by Donald M. Marcus

The speaker is from Baylor College of Medicine in Houston, Texas. He began the presentation by providing a list of some of the common alternative therapies available today. These included Chinese medicine, ayurvedic medicine, chiropractic, homeopathy, and naturopathy. He highlighted the fact that the therapies were not based on evidence and that they lacked scientific plausibility. He gave an outline of the history of many of these alternative traditions focusing on many of the negative outcomes that have resulted from the practice of these therapies over the centuries. He emphasized that any possible positive outcome of alternative medicines may be attributed to the placebo effect. Interestingly, the speaker noted that symptoms relieved by the placebo effect were not imaginary.

One of the areas that he focused on dealt with the general problems in the use of herbs. These problems include quality control issues, adulteration, toxicity, efficacy, misleading and false claims, and a lack of warnings about adverse effects. One might argue that many of the herbal preparations available on the market today are available in standardized extracts, but the speaker noted that the standardized extracts are based on marker components and not on biological activity.

The speaker complained about the fact that there are no reliable monographs on herbal preparations and that individual literature searches must be conducted. In his view, the bottom line on herbal preparations is this:

- The consumer of these products have no assurances about what they're getting in the bottle;
- The health claims are not based on scientific evidence (such as randomized control trials);
- There is a lack of information on the safety and warnings of these products;
- There is an unknown benefit/risk ratio.

Another area that the speaker discussed was chiropractic medicine. To summarize, he described chiropractic as spinal manipulation to treat mainly musculoskeletal disorders of the back and neck. Chiropractors were categorized as being either traditionalists who use only spinal manipulation and mixers who use spinal manipulation as well as diagnostic imaging, laboratory tests, ultrasound, massage, exercise and sell herbal preparations.

The speaker concluded that there is no strong evidence that supports the efficacy of manipulation as a treatment for back pain. Furthermore, there was a strong element of salesmanship in perceived efficacy. He noted that manipulation of the neck was potentially dangerous and that it was inappropriate to consider chiropractic as a broad-based alternative to conventional medicine.

Another form of alternative medicine that the speaker discussed was acupuncture. His evaluation of acupuncture was in part based upon the National Institutes of Health consensus on acupuncture. In this document, acupuncture was supported by evidence to treat nausea and vomiting secondary to surgery, chemotherapy, pregnancy, and pain after surgery.

Furthermore, he noted that acupuncture might be helpful for addiction, asthma, carpal tunnel syndrome, dysmenorrhea, fibromyalgia, headache, epicondylitis, low back pain, and stroke rehabilitation. Acupuncture may work through the activation of brainstem nuclei and inhibitory descending pathways, opioid and non-opioid mediators. He also mentioned that insertion of needles could elicit a powerful placebo effect.

The speaker concluded that acupuncture might be used in addition to conventional treatment (for example, medications) of some pain syndromes and possibly nausea. He went on to say that although it was safe there was no other sound evidence supporting its use for other proposed problems. Lastly, he commented that it was expensive, time-consuming, and uncomfortable for some people.

Overall, the speaker felt that the reasons for use of complementary alternative medicine were due to:

- Frustration and need for hope;
- A dysfunctional health-care system;
- Cultural bias; and
- Misleading and deceptive promotion.

Although the speaker had very few positive comments regards alternative medicine, he did finish off his seminar by listing a few things that practitioners of conventional or “Western” medicine can learn from the field of alternative medicine. These included:

- The importance of listening to patients;
- The need to help patients cope with stress; and
- The need to develop new approaches to communicating with the public.

2. Rheumatoid Arthritis -- Human Etiology and Pathogenesis I

This lecture was an abstract (summary of research results) presentation that discussed how joints are damaged in rheumatoid arthritis.

Initially I thought that this would be a very interesting topic, however, the knowledge level at which the presentation was given was well beyond my ability to understand all aspects of the presentation, but I did learn a few things.

I learned inside the joint of a person with rheumatoid arthritis is inflammation, and in that inflammation, there is a certain type of white blood cell present called a “macrophage”. Macrophages release a group of chemicals known as “inflammatory cytokines”. These inflammatory cytokines include interleukins and tumor necrosis factor alpha. It is these cytokines that induce a process known as osteoclastogenesis.

Osteoclastogenesis is the formation of a type of cell known as osteoclasts. Osteoclasts are responsible for the resorption of bone (in essence, the “disappearing” of bone), and this is in part how joint damage occurs.

With this knowledge, a relatively new group of drugs known as “biologic response modifiers” were developed which specifically target the tumor necrosis factor alpha (for example, infliximab/Remicade, or etanercept/Enbrel). If the effects of this inflammatory cytokine can be inhibited, then the damaging effects that inflammation normally has on bone, specifically joints, can be minimized or stopped.

3. Ankylosing Spondylitis Clinical Symposium (sponsored by a pharmaceutical company)

There are many misconceptions surrounding ankylosing spondylitis. Some common **misconceptions** are:

- That ankylosing spondylitis is rare;
- That it is a benign disease;
- That is a non-inflammatory disorder; and
- That is not “treatable”.

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Some facts reported by the session speaker included:

- There is a significant amount of disease progression in the first 10 years after disease onset;
- Typically, there is a delay in diagnosing the disease of up to five to eight years;
- Those patients who continuously used NSAIDs has less disease progressed as measured by x-ray than those who used NSAIDs (non-steroidal anti-inflammatory drugs) only as needed;
- Conventional drug therapy for and ankylosing spondylitis includes NSAIDs, however, they are often not strong enough to completely control the disease;
- Intra-articular steroids (cortisone delivered by needle directly into the joint) can reduce inflammation, but not for long periods of time and not in all people;
- Systemic steroids (such as prednisone) may work against inflammation, but often high doses are needed and there is only a subgroup of patients who respond to this type of therapy;
- DMARDs (disease modifying anti-rheumatic drugs) work mainly for peripheral arthritis and offer limited disease control for spinal disease; and
- Bisphosphonates (medications that help to preserve bone density and strength) show some benefit.

Based on the above, there is a clear need for the development of new drug treatments for ankylosing spondylitis. The biologics appear to be a new class of drugs that are effective in treating the disease. Nine international studies on the effective use of infliximab in the treatment of ankylosing spondylitis were reported. Infliximab was tested in almost 600 patients with clinical efficacy in 60 to 80 percent of patients. Etanercept was also shown to be effective in the treatment of ankylosing spondylitis.

4. Rational Management of Fibromyalgia, presented by Robert M. Bennett

“What are you actually treating in fibromyalgia?” Of course, as the speaker outlined, there is no simple and straightforward answer. He covered six areas that must be addressed when treating a person with fibromyalgia. These included:

- Education;
- Pain;
- De-conditioning;
- Psychological distress;
- Non-restorative sleep; and
- Associated syndromes.

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Education

Symptom “validation” is an important step in the education process for people with fibromyalgia, as is reassurance that fibromyalgia is non-destructive (no joint damage) in nature. Physicians should emphasize to their patients that treatment is not a “cure” and that it is important for patients to try focusing on “wellness”, rather than “illness”.

There is a need for patients to take an active role in their treatment plan and to openly discuss the touted “cures” for fibromyalgia with their physicians.

Pain

“Generators” of pain include injuries, neuropathies, inflammation, osteoarthritis, repetitive strain, and endometriosis to list a few. It was stressed that understanding the neuro-physiological basis of chronic pain could lead to more effective management of pain through the use of rational combination therapy.

Combination therapy includes drugs from the following categories: Membrane stabilizers, 5HT3 antagonists, SSRIs/SNRIs, NMDA inhibitors, and Alpha-2 adrenergic agonists.

De-conditioning (loss of physical condition)

De-conditioning is an area that needs to be addressed in people with fibromyalgia. Exercise can be both beneficial and detrimental. Benefits of exercise include:

- Psychological;
- Reduced muscle micro-trauma; and
- Improved functionality.

Risks of exercise include:

- Overtraining;
- Increased muscle micro-trauma; and
- Injuries.

Aerobic exercise was found to be helpful, however, the biggest issues regarding aerobic exercise were long-term compliance (“sticking with it”) and tolerance. Patients are recommended to start aerobic exercises two to three months after the start of drug therapy. Starting with “low impact” exercise is best (like cycling or swimming) is best to avoid eccentric muscle contractions.

The speaker recommended that both the person with fibromyalgia and their physician should think of exercise as a “medication”, to help reinforce the idea that exercise is a “treatment”.

Psychological distress

The speaker recommended cognitive behavioral therapy as a means of helping the person with fibromyalgia to manage psychological distress. Cognitive behavioral therapy helps to identify and reduce active illness behavior, and helps to improve the patient's coping strategies and self-efficacy.

Non-restorative sleep

The first step towards addressing non-restorative sleep is to rule out a primary sleeping disorder (like sleep apnea—erratic or difficult breathing when sleeping). If there is no primary sleeping disorder, then the patient should learn basic sleep hygiene measures, like limiting caffeine and alcohol intake, among others.

The physician's role should be to try to minimize pain at night and psychological distress. The medication recommended to help with the sleep included tricyclics, short acting hypnotics and muscle relaxants.

Finally, it is important for the physician to be aware of associated syndromes such as irritable bowel syndrome, irritable bladder, restless legs, postural hypotension, dizziness, cognitive dysfunction, cold tolerance, and many other insensitivities.

In conclusion, there is much that is exciting going on in the field of rheumatology at present, and by attending this conference, it enabled me to have just a brief glimpse at what the future holds. It was truly an overwhelming yet rewarding experience. **Pat Quon**

Arthritis Research is Making Great Progress, by Cheryl L. Koehn

This was my fifth consecutive ACR meeting and I left feeling encouraged that real progress was being made in a number of areas in arthritis research. Like my arthritis colleagues, Pam Montie and Pat Quon, I found this year's ACR meeting an incredible—but exhausting—experience.

On the clinical research side (studies where actual patients are involved), there were significantly more presentations that included the patient or consumer perspective, including the wonderful work being done by the OMERACT group. From the research presented, I could see that closer attention is being paid to what consumers/patients are saying are important or “meaningful” clinical outcomes (such as swollen joints, ability to walk a block, tie shoelaces, etc.).

To begin my report, I thought I would share with you some tips I have learned over the years on how to prepare for attending a scientific meeting such as the ACR (American College of Rheumatology) Annual Scientific Meeting, or the EULAR (European League Against Rheumatism) Scientific Meeting.

- ✓ If you are volunteering for or are a member of an arthritis organization and have a keen interest in research, and you want to help get the knowledge you have gained out to your arthritis community, approach the organization for sponsorship to a scientific meeting such as the ACR.
- ✓ Register for the meeting as soon as you hear about it. You can log onto the ACR web site at www.rheumatology.org to register on-line or to download and print off registrations forms that can then be faxed to their central office.
- ✓ Book your hotel as soon as possible. Each conference has a group of about 10 hotels which offer discounted rates to meeting attendees. Because the days are long and physically demanding, securing a hotel that is most conveniently located to the conference facility is critical—that is, unless you like riding on buses very early in the morning or late in the evening ☺
- ✓ Rest up before the meeting by planning a “light” week of work (if you have this flexibility) and leisure activity. As mentioned above, attending a scientific conference is physically challenging, so following basic disease self-management principles is a must.

- ✓ Find a “meeting mentor”. Good mentor candidates are another consumer or a researcher or health professional from your community who has attended a meeting of this type before.
- ✓ Review the scientific program with your meeting mentor in advance to determine your schedule. This may sound easy, but trust me, when there are over 30 different sessions one might attend at any given time, putting together one’s schedule is like working on a 10,000- piece jigsaw puzzle. For the ACR meeting, the ACR web site has a very helpful on-line scheduling tool that lays out all of the presentations you wish to attend in chronological order.
- ✓ The most popular sessions at the ACR meeting tend to be the plenary sessions (when the “big name” or premier research is presented) on arthritis, and the sessions where phase II and III clinical trial data and long-term drug safety reporting is presented. Arrive at these sessions a bit early to get a seat, otherwise, you run the risk of standing for an hour and half.
- ✓ A huge exhibit hall is open throughout the conference. In the centre of the exhibit hall are booths featuring everything from medical textbooks to the latest biologic response modifier. Usually, a lot of free merchandise is given out at the booths (not medications, but things like free magazines, writing pad, coffee mugs, pens, etc.)
- ✓ Around the perimeter of the booths are poster boards with summaries of all of the original research work that the ACR determined was scientifically worth presenting. Each day, a new set of posters go up and the researcher who led the project stands by the poster for a couple of hours so that meeting attendees can ask questions about their work.

For me, the best part of a scientific meeting is the poster sessions. You run into old colleagues and meet new ones while wandering along the poster boards, you stop and chat and trade ideas about your work, and discuss ways in which to move yours—or the other person’s—work forward.

- ✓ In recent years, industry has increased its activity to “one up” the competition to win their product a market advantage. Sadly, this type of competition is making its way into scientific programs.

Always be aware of who funded the research being presented. Typically, industry sponsored research offers less control to the principal researcher to determine the design of the study. The design of a study can help lead to conclusions that favour (or not) a product.

- ✓ Make sure you eat. I always find myself completely exhausted by 5:00 pm, and it is usually because I ran around from session to session without stopping for a break for food. Not smart.
- ✓ If you are lucky enough to attend a meeting such as the ACR, you must really commit to reporting on what you learned to the community. Although some of the science escapes us because it is presented at too technical a level, it is important to share with our arthritis community all that we experienced and learned.

So, enough tips for now, the following are a few of the sessions that struck me as being very important to write about and share with you.

1. Patient-physician Communication and Health Outcomes, presented by Dr Michael Ward

Communication is one way to judge a relationship between a patient and their physician. Power is an organizing principle in relationships, and can be categorized into three types: paternalism, consumerism, and mutuality.

Paternalism

The physician has all of the power, sets the agenda for the visit, the treatment and assumes the values of the patient. The patient is passive, seeing the physician in the role of “guardian”.

Consumerism

The patient has all of the power and sets the agenda for the visit. The physician takes on the role of “technician”, executing the patient’s will with little or no input or “voice”.

Mutuality

This is thought to be optimal for both the patient and physician. Mutuality means that both the physician and the patient have power, with the agenda for the visit, evaluation, and treatment being negotiated by both parties. Patient’s values are jointly examined with the physician in the role as advisor. The key aspects of care in patient-physician relationships are: visits medically functional, patients concerns/opinions fully expressed, information provided, patient participates with a responsible role in the decision making, and psychosocial concerns addressed and support provided.

So where do you fit in? Well, each one of us has different preferences in communication practices. Half of us prefer the collaborative or mutuality organizing principles. Ten percent prefer the consumerist organizing principle, and thirty percent prefer a paternalism organizing principle. Interestingly, more severe disease makes patients more passive (paternalism).

From the speaker's viewpoint, mutuality was the favoured organizing principle for patient/physician relationships because it supports the following key aspects of care:

- Visits are medically functional;
- Patient's concerns/opinions are fully expressed;
- Information is provided;
- Patients participate and have a responsible role in decision-making;
- Psychosocial aspects are addressed and support is provided.

One way to judge the quality of patient-physician communication is to assess the factors that lead to effective patient-physician communication. These include:

- Information giving;
- Assertions;
- Expressions of opinion;
- Agreement on problems;
- Reassurance;
- Emotional talk;
- Question asking;
- Expressing concern;
- Giving directions;
- Empathy; and
- Rapport building.

There are two ways to assess these factors; the first is through direct observation (as the communication happens), the second, through retrospective assessment (after the communication has occurred).

The speaker went on to discuss the specific health outcomes (results) that could be measured to give one an indication of the quality of patient-physician communication. The areas for assessment are:

- Patient satisfaction;
- Adherence;
- Health Status/Quality of Life; and
- Mortality (death).

Patient Satisfaction

Good communication between a patient and physician was highly related to increased patient satisfaction. In other words, the better one communicates with one's physician, the happier they are with the results of their decision-making. Patient satisfaction goes down when they were not able to express all of their concerns with their physician.

Adherence (sticking with something)

A patient's ability to adhere to treatment, for example, is assumed to follow their level of satisfaction. However, adherence is mostly associated with information giving by the physician or health care provider. Adherence is also associated with supportive comments by the physician. Adherence goes down when the physician asks questions of the patient.

Health Status

When the patient is given choices during the communication process, health status is improved. Patients who more actively participate experience greater symptom resolution and less anxiety.

In conclusion, the speaker went on to offer recommendations on things the patient and physician can do to improve communication:

- ✓ The patient can learn to better identify specific health problems and how to negotiate help for those specific problems during their appointment with their physician;
- ✓ The patient can attend courses such as the Arthritis Self-Management Program to learn more about active coping strategies;
- ✓ The physician can conduct "group visits" where patient-to-patient learning can take place;
- ✓ The physician can take communication training programs (although the speaker noted that these were typically not very successful);
- ✓ The physician can use a communication technique using the following formula:
 - Instruct
 - Restate
 - Explain
 - Reiterate
- ✓ The physician can use decision-making aids (such as a medication chart) to help the patient better understand and make treatment choices;
- ✓ The physician could discuss the decision-making process with the patient.

For additional tips on improving communication with one's health care team, read the October issue of [Arthritis News Update](#).

2. Medico-legal Aspects of Informed Consent and Standard of Care, presented by Allan Gibofsky

This was an interesting session on the legal aspects of informed consent. The informed consent process is central to medical treatment and participation in research, with the rights of the patient being paramount at all times.

The speaker noted that there were two “senses” of informed consent:

- Autonomous authorization – the ethical principle of respect for persons and their right to liberty;
- Social rules of consent – the process of obtaining the consent of minors, special forms and witnesses.

He then briefly described the informed consent process in three stages:

- “Threshold” – the beginning of the process when the decision-making capacity of the individual is determined and that their willingness to participate in a study is voluntary;
- “Information” – the next step in the process when information about the study is disclosed to the participant so they have a thorough understanding of their participation;
- “Authorization” – the final step in the consent process when the individual makes a decision about whether or not they will participate.

The speaker noted that it is important for those managing the consent process to remember the difference between “consent” and “assent”.

Consent is an informed, voluntary decision to participate, culminating from the above three step process.

Assent is simply an expression of willingness, not consent.

Required elements of the consent process are:

- ✓ A full description of the intervention (typically, a treatment), including:
 - The purpose of the research
 - How long the individual will participate
 - The procedures the individual will have to follow
 - The procedures which are experimental
- ✓ The potential benefits and risks;
- ✓ The alternatives to the intervention in the study;
- ✓ Protection of the confidentiality;
- ✓ For research involving greater than minimal risk, compensation and treatment, if any, for possible injury due to participation in the study;

- ✓ Contact information for those responsible for the study, such as the head study nurse or principle investigator;
- ✓ Unforeseeable risks;
- ✓ Costs to participation;
- ✓ Consequences of withdrawing from the study;
- ✓ New findings; and
- ✓ Number of participants.

The speaker concluded by highlighting three specific and ongoing challenges to the informed consent process:

- Physician recommendations may be perceived by the individual/patient as encouragement to participate, which is the equivalent of persuasion.
- Obtaining consent from minors;
- Obtaining consent in emergency settings.

3. Arthritis and Obesity, presented by John P. Foreyt

This was a fascinating talk and is a very important topic for those living with a chronic disease/disability like arthritis. Although the material presented was from the American perspective, it is nearly wholly transferable to the Canadian setting.

The risk of obesity

Obesity is a significant risk factor for osteoarthritis, and is less so, but still a risk factor, in rheumatoid arthritis. This is also true in the context of birth defects, cancers, cardiovascular disease, daytime sleepiness, deep vein thrombosis, pain, etc. In other words, obesity is an issue for tens of millions of people. (Visit www.arthritisresearch.ca/news/news08.htm to learn about breaking osteoarthritis research.)

Interestingly, a person's risk of becoming obese is accelerated when they become 15 pounds overweight, or if they have osteoarthritis in the hip, knee or hand.

The root cause of obesity

The speaker discussed the underlying causes of obesity, and overall, stated that the prevalence (frequency) of obesity is due to our environment. He offered these points to validate his statement:

- Children see 10,000 food commercials in a year;
- The average American consumes 3,400 calories per day;
- We live in the age of "super size" (now, a common marketing practice at fast food outlets).

The “state of the art” in nutrition

There is nothing new in nutrition. The origin of the today’s very popular “Atkins Diet” is the “Banting Diet” from 1864.

Losing weight

The speaker spoke at length about the best research-based approaches to losing and maintaining weight.

Cognitive Restructuring:

- Changing the way we think about losing weight is essential. It is important to have realistic expectations around weight loss—such as “slow is good”, and small changes are good;
- “Get a life”, in other words, do not make your life about your weight or weight loss, find a deeper meaning of life.

Stress Management:

- Physical activity increases one’s sense of well-being;
- Meditation (quiet contemplation) is a good “stress reliever”;
- Progressive relaxation—the process of tensing and then relaxing muscles.

Social Support:

- Having the support of one’s family is important in weight loss;
- Peer group support is important;
- Community support (for example, self-help or self-management groups) is important.

He also made the following general points:

- Keep a food journal: self-reporting food intake is critical to helping the individual understand how much and what types of food they are eating. However, recording accurately is just as important. Most people who keep a food journal underreport their calorie intake by a third.
- Keep an exercise and weight record to track progress.
- Identifying what stimuli (motivations) that causes a person to overeat is important. Once these are identified, stimuli controls can be developed. For example, most people break their “diet” at 4:30 in the afternoon. Knowing this, an individual trying to lose weight should try to make sure they are participating in some activity (other than cooking) at that time of day to manage this period of the day.

Predicting weight loss

A key “predicting factor” that increases an individual’s chance of weight loss is **exercise for at least 60 minutes per day at greater than six “mets”, such as running, cycling, aerobics, dancing, etc.** The obese individual should focus on a healthy lifestyle rather than on “losing weight, and eat 3 bites less than they normally would at each meal.

Predicting weight maintenance

An individual’s chances of maintaining their weight if the following predictor factors are in place:

- Eat a calorie-controlled, low-fat diet (low fat is better for maintenance);
- Eat breakfast—90 percent of those people in research studies who did, kept the weight off;
- Self-monitor food intake and weight regularly;
- Be physically active – at least one hour per day.

The speaker concluded his presentation by offering the following additional points on obesity and arthritis:

- ✓ Focus at all times on a five to 10 percent weight loss;
- ✓ Focus on “health” and “energy”
- ✓ Keep diaries or journals (food, weight and activity);
- ✓ Gradually reduce dietary fat;
- ✓ Convert feelings of food deprivation (removal) with ones on making healthy food choices;
- ✓ Get involved with social support groups;
- ✓ Take individual responsibility for the things about one’s weight or weight loss that they have control over.

This concludes my brief report on a few of the sessions and workshops I attended at the ACR meeting. I returned from the meeting highly motivated to get this information out to the arthritis community in the most expedient and meaningful way possible.

It is my sincere hope that the readers of this report will learn from our various overviews of the sessions we attended, and that they found this format accessible and of benefit.

Cheryl L. Koehn

Feedback

Getting direct feedback from people living with arthritis is important to the work of Arthritis Consumer Experts (www.arthritisconsumerexperts.org) and the Arthritis Research Centre of Canada (www.arthritisresearch.ca).

If you would like to share your thoughts about this report, please email Arthritis Consumer Experts at info@arthritisconsumerexperts.org, and the Arthritis Research Centre of Canada at alehman@arthritisresearch.ca

Thank you for taking the time to read this report. We hope you found it of interest and value to you or the person you know living with arthritis.