JointHealth monthly

Arthritis research

breaking new ground for people living with arthritis

Each year, the best arthritis researchers in the world come together at the

American College of Rheumatology (ACR) Annual Scientific Meeting. There, the latest and most ground-breaking research is reported and arthritis researchers and allied health professionals (such as physiotherapists and occupational therapists) learn from one another and exchange ideas about how to advance scientific discoveries to improve the lives of people living with arthritis around the world.

The 2007 ACR meeting was held in Boston, Massachusetts. During the six-day meeting, approximately 12,000 attendees attended lectures and participated in workshops on a wide variety of topics, including:

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- drug safety and effectiveness;
- alternative therapies;
- pain;
- pregnancy issues and fertility;
- issues specific to many of the more than 100 different types of arthritis.

Although it can take many years to learn the results of some research studies, tremendous gains in arthritis knowledge were reported last year, including:

- New molecules involved in inflammatory arthritis;
- Improved knowledge around prevention strategies in osteoarthritis;
- Identification of new risk factors for developing several types of arthritis;
- New strategies for early detection of many forms of arthritis;
- Further understanding around the root causes of different types of arthritis;
- Improvements in joint-replacement surgical techniques;
- Better understanding of the role played by vitamin and mineral supplements in people with arthritis;
- The effectiveness of acupuncture in both osteoarthritis and rheumatoid arthritis and other complementary and alternative treatments;
- New adaptive devices to help people living with arthritis with their daily tasks, both in the

home and at work;

- Impact that arthritis and disability has on people with the disease, their families, friends and the workplace;
- Costs of arthritis and its impact on economies and health-care systems;
- New, improved ways for physicians to communicate with patients, among others.
 Participation in the annual ACR meeting is open to all members of the scientific and medical communities who have a special interest in researching issues related to arthritis. Because of the tremendous difference that research makes in the lives of people with arthritis, ACE believes that it is vitally important that people who live with disease are kept informed of interesting and important research developments. In this issue of JointHealth monthly, we are pleased to present brief summaries of just a handful of the thousands of research papers presented at last year's meeting.

For more in depth information about arthritis research, you can visit the following websites:

- www.rheumatology.org (American College of Rheumatology)
- www.arthritisresearch.ca (Arthritis Research Centre of Canada)
- www.nlm.nih.gov/index.html (National Library of Medicine, National Institutes of Health)

If you would like to hear or view some of the actual workshops from last year's ACR meeting, audio recordings (CD or MP3) and video recordings are available for purchase on the ACR website **www.rheumatology.org** (under ACR Products on their homepage). Depending on your interests, you may purchase the full conference recording, a group of workshops by topic, or various sessions individually. (Please note that most of these recordings and videos are presented in scientific language, not "public friendly" language.)

Lifestyle & family

Work & disability

Coping

- Across diagnoses (for example osteoarthritis, rheumatoid arthritis, lupus, ankylosing spondylitis), people with arthritis reported relationships, social and leisure activities as being impacted by their disease. They also reported experiencing high levels of depression and anxiety. Body-image and self-esteem were also found to be significantly impacted by arthritis.
- Different studies on lupus, fibromyalgia, Sjogren's syndrome, and osteoarthritis demonstrated that people with arthritis have higher levels of depression, anxiety, fatigue, and generally, lower levels of quality of life, when compared with people without arthritis or another significant health condition.
- Osteoarthritis pain flares were demonstrated to coincide with when people were also experiencing decreased psychological health (for example times of increased stress or depression).
- A study on whether depression was linked to how people respond to behavior therapy (for example, weight loss and exercise intervention) as a way to decrease pain in knee osteoarthritis. Researchers found that high levels of psychological distress may relate to people responding poorly to these types of interventions.
- A study on the effect of lupus on sexual health of women found that women, particularly young women, had "significant sexual and procreation concerns". These include decreased desire for intimacy, avoidance of sexual activity, and fears that medications would affect the ability to conceive. Women with poorer health status reported greater concerns.
- Young men living with polyarticular and juvenile idiopathic arthritis reported sexual health satisfaction and desire even though they reported having increased joint pain during sex.

- Several research studies showed that people with arthritis, particularly inflammatory arthritis conditions, frequently missed work (high levels of work absenteeism).
- Pain and fatigue related to arthritis were directly related to people not being able to work or to people taking a higher number of days off work.
- To minimize the number of total work days missed, researchers recommended people with arthritis try to: change work hours, change the type and nature of work, and accept that sometimes taking one day off to rest can prevent the need for taking a long period off due to a flare of disease activity.
- One study showed that detailed and timely occupational therapy for people with arthritis helped people with their arthritis symptoms and helped them stay at or return to work.
- Studies compared medication treatment options and found that when adalimumab (Humira®) and methotrexate were taken together (compared with taking only methotrexate), people missed fewer work

"In many studies, exercise was demonstrated to help manage pain, fatigue, depression, and other emotional impacts of arthritis..."

days, had greater improvements in work performance, and had a greater likelihood of keeping or finding a job. People also experienced improvements to psychological health (for example, less stress, depression or anxiety).

- In many studies, exercise was demonstrated to help manage pain, fatigue, depression, and other emotional impacts of arthritis on quality of life.
- Several studies also highlighted the role that exercise can play in helping people return to work more quickly. Exercise can minimize the number of sick days taken and improve productivity at work.

- A study comparing different coping styles of adults with different rheumatic diseases found that patients with fibromyalgia have the greatest difficulty with their illness.
- A different study on coping looked at the impact of stress and coping in children and adolescents with fibromyalgia. This study found that people who had access to positive social support and who felt confident and capable of managing their disease were likely to experience less of the impact of fibromyalgia on quality of life, depressive symptoms, and pain.
- One study looked at the effect of spirituality (for example, prayer, meditation, reflection) on health outcomes, comparing older adults with and without arthritis. Researchers believed that an increase in spiritual activities may be linked to more energy and less depression. The authors concluded that spirituality may positively influence the mental health and wellbeing of older adults with arthritis.
- Researchers were interested in whether coping and social support impacted people's treatment outcomes. These studies looked at people with lupus and people who had recently had a total knee replacement for knee osteoarthritis. They found that people with high levels of social support were more likely to stay with their treatment, while depression was more likely to lead to people not staying with the treatments.
- Both of these studies, along with the study on spirituality, recommended that future arthritis research and treatment programs use self-management strategies that focus on psychosocial factors such as decreasing depression and anxiety. Other recommendations included increasing people's beliefs in their capabilities to manage their arthritis through positive coping strategies.
 Examples of positive coping strategies include: asking for help, knowing and accepting limits, and using assistive mobility devices.

Medications

Benefits and side effects

- A number of studies on biologic response modifiers to treat inflammatory arthritis were reported, including studies on abatacept (Orencia®), adalimumab (Humira®), etanercept (Enbrel®), infliximab (Remicade®) and rituximab (Rituxan®).
- One study reported that even though people with rheumatoid arthritis using anti-TNF therapies were significantly concerned about their cost, potential for side effects, long-term safety, injection site pain and dislike of shots, these concerns did not stop them from taking the medication.
- Three large studies were completed on the use of anti-TNF therapies during pregnancy and the incidence of birth defects. Two studies did not reveal any increased risk for birth defects, miscarriages, or low birth weight, but one found that a statistically significant number of birth defects in babies born to mothers who used an anti-TNF during pregnancy did occur and noted that further research is needed in this area.
- Abatacept: Studies found significant improvement in patients' ability to participate in their daily life activities with abatacept use. Another study found that abatacept reduced sleep disturbances and improved overall sleep.
- Adalimumab: Studies on adalimumab and people with ankylosing spondylitis showed an improvement in quality of life after 2 years of use.
- Infliximab: A two-year study showed meaningful and sustained improvement to spinal mobility with infliximab use in ankylosing spondylitis.
- Depression, anxiety, and disease activity were found to improve in a study of infliximab and patients with rheumatoid arthritis.
- Rituximab: Use of rituximab in ankylosing spondylitis was found to be both effective and safe, improving fatigue and pain symptoms without risking further immune system problems.
- Etanercept: A study looking at the 10-year safety and effectiveness of etanercept in people with rheumatoid arthritis reported the medication continued to be safe and effective. Higher rates of lymphoma were reported in the study group, but it is not known if this was related to etanercept use or to the fact that people with rheumatoid arthritis are already at a higher risk of developing lymphoma.

Non-medication treatments

Acupuncture, vitamin D, self-management programs

- One study looked at why more and more people are turning to complementary and alternative medicine (CAM) to treat their arthritis. The researchers found that people doubted the treatment effect of traditional western medicine (for example, pharmaceutical medications) and had fears around long-term medication side-effects.
- A large study conducted a systematic review of the current literature/research that exists around the use of acupuncture for rheumatoid arthritis. The authors concluded that though acupuncture is widely used for pain relief, there is scarce evidence to determine the effect of acupuncture on rheumatoid arthritis. Though some studies showed that acupuncture might be helpful in treating rheumatoid arthritis pain, researchers recommended that more studies must be done to fully understand the role acupuncture can play in managing arthritis pain.
- Studies looked at use of acupuncture for knee osteoarthritis by comparing outcomes with those from a 'sham' or 'fake' acupuncture treatment. Researchers found there was no difference in treatment outcome between the traditional and 'sham' acupuncture treatments. Similar findings were found when exploring the use of acupuncture for fibromyalgia.
- Several studies reported the finding that a lack of vitamin D was common in rheumatoid arthritis patients (including young children).
- Vitamin D deficiency was related to increased pain and difficulty performing activities of daily living.
- Low vitamin D levels were also found to be associated with greater pain and problems of mobility in people with knee osteoarthritis.
- The common conclusion across all studies on vitamin D was that further studies on the role of vitamin D in mediating arthritis pain and symptoms is needed.

Self-management (SM) programs:

- Online/Internet and telephone selfmanagement programs were viewed as positive and cost-effective alternative strategies to reach more people with arthritis and help them better manage their arthritis symptoms.
- Researchers recommended that all newly developed self-management programs be made relevant to the people participating for example: disease, age of participants, and stage of disease (recently diagnosed or longterm disease).

Healthcare services

The value of the patient perspective

- Many studies highlighted the issue that patients and doctors view arthritis experiences differently.
- One study looked at doctors and patients' perceptions of the physical and emotional impacts of lupus and found that doctors tended to underestimate the impact of lupus on quality of life.
- Another study on social isolation revealed that doctors did not recognize the same levels of social isolation as reported by patients with arthritis.
- With respect to satisfaction of health care, one study found that higher satisfaction was linked to physician characteristics such as accessibility and discussion/monitoring of medication side effects.
 - "...doctors did not recognize the same levels of social isolation as reported by patients with arthritis."
- A study on health literacy (the ability to understand medical and health language and information) revealed that people often have difficulty communicating with their health care professionals and understanding written health materials provided to them by their health care team.
- A study on health care satisfaction and fibromyalgia recommended that the patient perspective be valued and included in treatment evaluations as a means to improve and promote better relationships between patients and their doctors.
- Another study examined ways to improve the patient-physician relationship, in the treatment of osteoporosis. Researchers found that doctors valued reporting results of bonedensity tests directly to their patients as this gave doctors a better opportunity to discuss treatment options. (

Information about the studies discussed in this issue can be found here: Abstract Supplement. Arthritis Rheum 2007:56:S1-S892.

Arthritis Consumer Experts

Who we are

Arthritis Consumer Experts (ACE) provides research-based education, advocacy training, advocacy leadership and information to Canadians with arthritis. We help empower people living with all forms of arthritis to take control of their disease and to take action in health care and research decision making. ACE activities are guided by its members and led by people with arthritis, leading medical professionals and the ACE Advisory Board. To learn more about ACE, visit

www.arthritisconsumerexperts.org

Guiding principles and acknowledgement

Guiding Principles

Health care is a human right. Those in health care, especially those who stand to gain from the ill health of others, have a moral responsibility to examine what they do, its long-term consequences and to ensure that all may benefit. The support of this should be shared by government, citizens, and non-profit and for-profit organizations. This is not only equitable, but is the best means to balance the influence of any specific constituency and a practical necessity. Any profit from our activities is re-invested in our core programs for Canadians with arthritis.

To completely insulate the agenda, the activities and the judgments of our organization from those of organizations supporting our work, we put forth our abiding principles:

- ACE only requests unrestricted grants from private and public organizations to support its core program.
- ACE employees do not receive equity interest or personal "in-kind" support of any kind from any health-related organization.
- ACE discloses all funding sources in all its activities.
- ACE identifies the source of all materials or documents used.
- ACE develops positions on health policy, products or services in collaboration with arthritis consumers, the academic community and health care providers and government free from concern or constraint of other organizations.
- ACE employees do not engage in any personal social activities with supporters.
- ACE does not promote any "brand", product or program on any of its materials or its web site, or during any of its educational programs or activities.

Thanks

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Disclaimer

The material contained in this newsletter is provided for general information only. It should not be relied on to suggest a course of treatment for a particular individual or as a substitute for consultation with qualified health professionals who are familiar with your individual medical needs. Should you have any health care related questions or concerns, you should contact your physician. You should never disregard medical advice or delay in seeking it because of something you have read in this or any newsletter. (

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