

## Research Program of Pain and Fatigue in OA

**People living with osteoarthritis (OA) place pain and fatigue as the number one priority** for OA researchers. Despite this, little is known about either. As researchers, we don't know what people with OA mean when they speak of pain or fatigue, or whether any available measures capture these features. This is why Dr. Gillian Hawker's research project "Determinants and Consequences of Pain and Fatigue in OA Using a Bio-psychosocial Approach" is so timely.

OA significantly impacts quality of life, ranking among the top ten causes of disability worldwide. People with OA have identified pain and fatigue as having the greatest impact on the quality of their lives but are too often told that they're just getting older and that these complaints are a normal part of aging. This leads to major confusion and frustration among people with OA and their health care practitioners around how best to deal with these complaints. Thinking that OA is an expected part of aging is a barrier to research directed at understanding what causes these complaints, and how they might be relieved.

A team of researchers with common interests and expertise in pain, fatigue/sleep, mental health, aging and OA, and people living with arthritis, has been assembled to work together to better understand pain and fatigue in OA. This new research program, lead by Dr. Gillian Hawker at the Canadian Osteoarthritis Research Program, aims to find out how the common symptoms of OA, including

**Dr. Gillian Hawker, MD, MSc., FRCP(C)** is the Director of the Canadian Osteoarthritis Research Program. She is a Staff Rheumatologist at the Women's College Campus of Sunnybrook and Women's College Health Sciences Centre, an Adjunct Scientist at the Institute for Clinical Evaluative Sciences and a Senior Scientist with ACREU, the Arthritis Community Research and Evaluation Unit. She is also the Director of the Clinical Epidemiology Program in the Department of Health Policy Management and Evaluation at the University of Toronto.

Dr. Hawker's research focuses on two common musculoskeletal diseases of aging: osteoarthritis and osteoporosis. Her OA research focuses on examining gaps in access to OA care, in particular hip and knee joint replacement. She also investigates factors affecting arthritis pain and disability over time in people



with OA. Dr. Hawker's current project (featured here) examines how the common symptoms of OA, including pain, fatigue, mood and reduced sleep quality impact people living with OA physically, psychologically and socially.

pain, fatigue, disordered mood and reduced sleep quality, impact people living with OA physically, psychologically and socially. The inter-relationships among pain, fatigue, and mood and how these relate to other factors, such as coping behaviours, access to care, family support, activity limitation, and use of established treatments for OA, will be explored.

This research will result in major breakthroughs in our understanding of pain and fatigue in OA. In particular, we will identify modifiable risk factors for these symptoms in OA. Knowing which

factors can be modified will help with the design and implementation of treatments targeted at these risk factors. Our research will, in turn, ultimately lead to a reduction in the burden of illness in the population due to this very common condition, OA.

This research project along with "Tooling Up for Early Osteoarthritis: Measuring What Matters" (another New Emerging Teams (NET) project, highlighted in our first issue) has been funded by the Canadian Institutes of Health Research (CIHR) and the Canadian Arthritis Network (CAN).

# The “Pain and Fatigue in Osteoarthritis” Research Team:

The columns beside each team member represent some of the projects currently underway. Investigators not yet associated with projects will be involved in future projects. We are also pleased to acknowledge the many other researchers who are contributing to the projects, but are not specifically part of the New Emerging Teams (NET) investigator list. For more information on these or our other projects, please contact our research office at 416.323.6218.

| The Project #s |   |   |   |   |   |   |   |   | The Researchers   |
|----------------|---|---|---|---|---|---|---|---|---|
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# Projects Underway:

These brief profiles cover the projects that have been approved and are underway. We will be profiling individual projects in future issues, to help people understand more about the research and its importance in daily living.

## #1

### Study of Arthritis in Your Community

The Study of Arthritis in Your Community, which started in 1995, will continue to follow an established group of more than 1000 older individuals from Ontario with hip and knee OA. The current five-year follow-up study will focus on the experiences of pain and fatigue in people living with OA.

Through individual interviews and community discussions, we will look at the relationships between OA pain, fatigue and mood, and study how the symptoms of OA impact those living with this condition physically, psychologically and socially. Participants are asked about their arthritis pain and disability, fatigue and sleep habits, mood, family support and coping strategies. We are also collecting information on what people do to manage their OA including the use of various treatments and therapies such as medications and exercise. Greater understanding of the inter-relationships among these factors will enable the development of new treatments, targeted to individuals in the context of their families and the community.

## #2

### Sleep and Osteoarthritis

Does your arthritis keep you up at night? Little is known about the sleep quality of people with OA. Many people may not have considered the possibility that sleepiness and nighttime sleep disruption may contribute significantly to arthritis related aches and pains. To learn more about the physiological aspects of sleep and sleepiness, individuals with OA will be participating in daytime sleepiness and overnight sleep assessments at the Sleep Lab at Sunnybrook and Women's College Health Sciences Centre. This study will help us better understand the sleep patterns and behaviours among people living with OA.

## #3

### Common Sleep Habits Questionnaire

What's the best way to measure one's sleep? A thorough review of existing sleep measures revealed that there are no reliable or valid measures of sleep, nor were any found to be suitable for use in people with OA. As a result, we have embarked on the development of a new sleep quality measure, appropriate for use both in clinical practice and clinical studies. The new Common Sleep Habits Questionnaire will be used in our research projects to examine the relationship among pain, fatigue and sleep in OA.

## #4

### What does an improvement in self-reported osteoarthritis pain and disability really mean?

Current understanding is that, even with medical treatment, OA progresses slowly until joint replacement surgery becomes necessary. Prior work by our group has identified that, among study participants, approximately 25% of people with advanced hip and knee OA reported improvements in their pain and physical disability over a five to seven-year period. There are at least two explanations for such improvement: they truly have improved or, as the disease progresses, individuals adapt to living with OA by changing their expectations or eliminating activities that aggravate their arthritis.

In 1997 and 2004, volunteers with OA completed joint examinations, hip and knee x-rays and questionnaires about their arthritis symptoms and disability. We used this information to determine if changes in self-reported symptoms and disability over time were associated with changes in clinical and x-ray findings. Did their arthritis really get better? We did not find a relationship between changes in self-reported pain and function and changes in OA on x-rays or physical examination. In other words, those who reported significant improvements in their arthritis pain and disability were just as likely as those who did not to have had worsening of their arthritis based on clinical examination and x-rays. This means that the severity of one's arthritis symptoms isn't always reflected in clinical assessments or x-rays. This study underlines the limitations of existing tools to measure changes in OA symptoms over time and highlights the need for better ways to assess changes in OA.

## #5

### Enhancing the Measurement of Pain in Individuals with Hip or Knee Osteoarthritis

Among people with OA, pain is the number one reason for doctor visits and for joint replacement surgery. Despite this, little is known about the quality and characteristics of OA pain, or changes in OA pain over time with disease progression. Greater understanding of the key features of pain that trigger changes in physical activity and/or mood, and that drive decision making around the use of treatments (such as joint replacements), would help to develop tools to assist clinicians. It would also provide information to base the development of outcome measures for clinical trials of new treatments in OA.

As part of an international collaboration, this study is using focus groups to increase our understanding of the natural progression of pain

*continued ...*

## Projects Underway *continued*:

in OA and one-on-one interviews to determine which aspects of the pain experience are most distressing. From data collected in this study, we will develop different pain scenarios that describe the typical OA patient's pain experience from early to late disease. These scenarios will provide the basis for development of pain measures in OA.

### #6

#### **Osteoarthritis and Depression**

Living with chronic pain disorders presents many challenges. However, the connection between mood and chronic pain is not well understood. Little is known about the mental health of people living with arthritis, particularly how OA pain and fatigue are related to mood. Using data collected in the Study of Arthritis in Your Community, we were able to take the first steps in determining the prevalence and severity of depressive symptoms among people living with disabling hip/knee arthritis. Among older adults with OA in this study, the prevalence of depressive symptoms is high. Of particular interest, depressive symptoms appear to be higher among individuals with greater OA pain and disability and among those who are trying to cope but perceive that their coping efforts are unsuccessful. These results suggest that strategies to improve coping efforts may assist OA sufferers who experience depressive symptoms.

The next step is to examine how valid the CES-D, a screening tool used to identify individuals that may be at risk for depression, is as a measure of clinical depression in people with OA. This will be done by comparing self-reported scores on the CES-D to clinical interviews using diagnostic criteria. This study will potentially lead to recommendations for clinical practice in the treatment of the individual living with arthritis.

### #7

#### **Profiles and Patterns of Medication Use among Older Adults with Osteoarthritis**

The symptoms of OA are frequently managed with medications, yet these medications are associated with a number of potentially serious side effects. Age-related changes and the presence of other chronic diseases can increase the risk of drug-related problems. In addition, the chronic nature of OA results in long-term use of medications and suggests variation in drug use over time. We have a unique opportunity to study the patterns of medication use over time among a sample of older adults with OA. From speaking to individuals with OA, we know that adherence to painkillers is low compared to other medications. This suggests that we need to re-evaluate how pain medication is prescribed for OA and keep in mind that the effectiveness of pain management in OA needs to account for adherence behavior in older adults. Using data from the Study of Arthritis in Your Community, we are going to further describe and explain patterns of pain medication use in this population, focusing specifically on the inappropriate under-use and over-use of pain medication, and potentially high-risk drug-drug and drug-disease combinations.

### #8

#### **Mood Medication Use and Osteoarthritis**

Do individuals living with OA use mood-altering drugs? Data collected during the Study of Arthritis in Your Community between 1999 and 2003 has been linked with the Ontario Drug Benefits database, a database that contains information on the use of medications covered by the province for people 65 years of age or older. This project will examine patterns of medication use, including the prevalence of prescription medications for mood disorders, among elderly individuals with OA. We will also be able to identify factors that predict certain patterns of medication use.

### #9

#### **Fatigue in Osteoarthritis**

Does your arthritis "wear you out"? Fatigue is not routinely evaluated in OA and has only been considered in a limited number of studies. This does not negate the significance of fatigue in OA. Fatigue in inflammatory rheumatic disorders has been found to be associated with pain, poor sleep quality and psychological factors such as depression, anxiety, stress and helplessness. Complicating the study of pain and fatigue in OA is the fact that many of the symptoms of OA may overlap with those of depression. Further, measures of depression include items that may also be found in measures of fatigue (e.g. lack of energy). In order to thoroughly understand fatigue in OA, it is necessary to consider the multi-dimensional nature of fatigue and to determine if pain, fatigue and depression are distinct or hybrid concepts in the context of OA. This project will describe the relationship between fatigue and pain, depression and OA disability as well as evaluate the best way of assessing fatigue in people living with OA.

#### **Thanks**

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And special thanks to The Arthritis Research Centre of Canada for administrative and hosting assistance.



# Living with Osteoarthritis

A personal story written by Olive Thorne: a person with OA, living in Edmonton, and a consumer collaborator with Dr. Gillian Hawker's research project.

"Today was my annual medical checkup. I'm almost three-quarters of a century old. Fortunately for me I have a good family doctor, the same one for about 15 years. Aside from my OA, I am in good health, so today I focused on my annual request to him for a referral to a rheumatologist. (My genetics is riddled with arthritis; I have two sisters, one who was struck down at the age of 70 with severe OA and RA, and another who has recently been diagnosed with sarcoidosis but who at 85 has no sign of OA!) I started the dialogue by explaining about the increasing OA in my neck, back, hip, knee and shoulders. He, as usual, muttered on that my problem was that I didn't have

any inflammation. He agreed though that if I weren't as active as I am, I would be in terrible shape. As I left, he was vaguely muttering something about a rheumatologist. Perhaps he's waiting for some of his own test results. Perhaps he's waiting for me to make the same request next year!

I can remember when I first experienced painful problems with my neck. I was in my late 30's trying to work at a stressful job in the daytime and attending university classes in the evenings. I coped with the pain until it temporarily eased, and breathed a sigh of relief ... until the next attack. Today I realize that this was the start of OA but who would have thought of that diagnosis then? Also at that age, I was almost crippled after participating in strenuous sport, another early sign of OA. Today, many 35 to 40 year olds tell me they suffer pain after strenuous activity

but they also seem to assume, as I did, that that is the way it is—no one mentions early OA! At my age now, this sore neck and after-sports stiffness has turned into a constant fight to fend off the debilitating effects of OA.

If I have been successful this year in being referred to a rheumatologist, I am hoping his prognosis will help me decide my future. I have grandiose ideas about renovating my house next year. So, will I renovate or will I troop back to my family doctor with another request for a referral to a rheumatologist?"

(As a side note: I recently (fall of 2005) attended a National Scientific conference as a patient involved in Dr. Gillian Hawker's Pain and Fatigue research project. There I met a rheumatologist from Vancouver who has now helped me get a referral to a rheumatologist in my hometown of Edmonton. Hurray!!)

## Osteoarthritis and You: "Your Link to Osteoarthritis Research in Canada"

People living with OA "put up with" the symptoms, whether they are just getting it or have lived with it for many years. Along with some family physicians, many people with OA believe that nothing can be done to ease the pain, suffering, and loss of function and daily activities caused by this disease. But the latest OA research is rapidly changing this view, and those who conduct and participate in the research are eager to share their "breaking news" with you.

OA and You is a new quarterly newsletter written by people living with OA and leading Canadian arthritis researchers. It will focus on getting the latest research information about OA out to family physicians, the health research community, people with OA and the public, as quickly as possible. By getting the latest information about the disease out to those affected by it, the disease can be better managed by health care professionals and people living with it can enjoy improved quality of life.

With a distribution to approximately 15,000 family physicians across Canada (in both French and English), OA and You will also serve as a link between researchers and

people living with the disease who want to be more informed and educated about OA as well as participate in short surveys, get involved in focus groups or "pilot" studies, or participate in clinical trials.

### Project Team Members:

|                    |                    |
|--------------------|--------------------|
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| Jay Fiddler        | Cheryl Koehn       |
| Anne Fouillard     | Jean Légaré        |
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### Pain and Fatigue in OA

### Consumer Collaborators:

Marg Elliot (Moncton, NB) and  
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### What do you want to know?

*Osteoarthritis and You* will be an invaluable information source. We encourage you to read this issue and to tell us what you think about it. We welcome your ideas for articles in future issues.

Please email your comments and ideas for future issues to:

oaandyou@arthritisresearch.ca  
Thank you.



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