

The JointHealth™ Survey on Arthritis Treatment and Care

As part of its ongoing effort to bring the voices and experiences of people living with arthritis to the public, medical and research communities and government, Arthritis Consumer Experts (ACE) recently conducted the JointHealth™ Survey on Arthritis Treatment and Care to find out what readers who live with arthritis need or want in terms of their arthritis treatment and care.

This issue of JointHealth™ monthly is devoted to reporting back to readers and getting the important information gathered through the survey out to those caring for, or working on behalf of, people living with arthritis.

Not surprisingly, the survey responses mirrored what current academic-based arthritis research is telling us: there are significant gaps in treatment and care for people living with arthritis. From insufficient provincial and territorial government reimbursement for prescriptions medications, lack of information and facilities aimed at promoting arthritis-appropriate exercise programs, to lengthy wait times to see arthritis specialists and undergo surgery. Despite having a "universal health care system", people with arthritis are receiving poorer quality service and fewer treatment options than people living with cancer or HIV and this is having a profoundly negative impact on their disease and quality of life.

Similar to other acute or chronic diseases, research in arthritis is conclusive that receiving

an early diagnosis is vitally important to slowing or stopping disease progression resulting in joint pain, damage and disability. Current research also confirms that a multi-disciplinary model of arthritis treatment and care produces the best health outcomes or "results" for the person living with the disease. Alarming, current models of arthritis treatment and care do not reflect "state of the art" scientific and medical knowledge.

What makes up an ideal treatment and care model for people with arthritis? The foundation comprises these three important pieces:

1. Research – knowledge generated by public and private medical research communities informs how "state of the art" treatment and care is developed, delivered and monitored

2. Awareness and education – awareness and education programs are research knowledge translated into easy-to-understand language that researchers, physicians, governments and consumers/patients use to improve their awareness, control, treatment and care of arthritis

3. Access to treatment and care – research knowledge is translated into time and cost efficient pathways of care by experts in the field and health care decision-makers

Public awareness around arthritis

issues comes in many forms, be it writing a letter to your MLA urging government to provide coverage of essential arthritis medications or sharing your arthritis story with others in the media. Education around various treatment options and the role of a treatment plan is important for people with arthritis because it increases the likelihood they will adhere to their treatment plan and better manage their arthritis symptoms. Continuing education is also necessary to keep on top of the current treatment and research advancements.

When comparing what is known to be the best model of care for people with arthritis to the JointHealth™ Survey on Arthritis Treatment and Care responses, we learn very quickly that respondents to the survey are not getting what they want or need.

For example, inside this issue you will read that 23 percent of respondents with ankylosing spondylitis—a type of arthritis that affects the spine—waited one to three years to receive a confirmed diagnosis. Given that a delay in diagnosis can lead to permanent joint damage and disability, the health care system must be "re-modeled" to better respond to the need for early diagnoses.

To learn more about what people responding to the Survey said, read this month's feature article: **JointHealth™ Survey on Arthritis Treatment and Care: The results are in.**

For more information on treating inflammatory arthritis and osteoarthritis, please visit the JointHealth™ Monthly archive for March 2007 and December 2007:

<http://www.arthritisconsumerexperts.org/news/2007-March.cfm>

<http://www.arthritisconsumerexperts.org/news/2007-December.cfm>

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JointHealth™ Survey on Treatment and Care in Canada – The results are in

In November 2007, Arthritis Consumer Experts (ACE) developed and administered an internet-based survey to gather information on the healthcare and treatment needs of people living with arthritis.

Timely access to treatment and care is critical for people living with arthritis. Research shows that delays in accessing appropriate treatment and care can result in higher rates of disability, increased joint damage, increased pain, and significant reduction in quality of lifeⁱ.

Despite this, research tells us that many Canadians living with arthritis are not receiving timely and/or effective treatment or care when and where they need itⁱⁱ. There are many reasons for this, including:

- Lengthy delays in getting referred to an arthritis specialist (rheumatologist)
- Lengthy delays in getting an appointment to see a rheumatologist
- Patient characteristics (for example, age, gender and social or economic status)
- Disparities in reimbursement coverage for medications through provincial or territorial health plans or private health insurance.

While research provides us with important information on these issues, too often it does not ask people living with arthritis where they feel their care and treatment issues are not being addressed. That is why ACE asked its members and JointHealth™ monthly readers—people living with arthritis—to share their views about arthritis treatment and care.

What you told us: Key Survey findings

Getting an arthritis diagnosis:

A significant challenge

In order to receive timely access to treatment and care, a person needs a diagnosis. Yet, research indicates that this is not always an easy or simple process. Diagnosis times may vary according to:

- gender
- age
- type of arthritis
- place of residence
- access to specialists, specifically rheumatologistsⁱⁱⁱ.

As proper diagnosis is central to accessing treatment, we asked people to share their experience of receiving a diagnosis for their primary arthritis condition. To do so, we asked two questions:

- The length of time it took to receive this diagnosis from the first visit to a health care professional for their symptoms.
- The number of health care professionals individuals saw before receiving their diagnosis.

Here are the results:

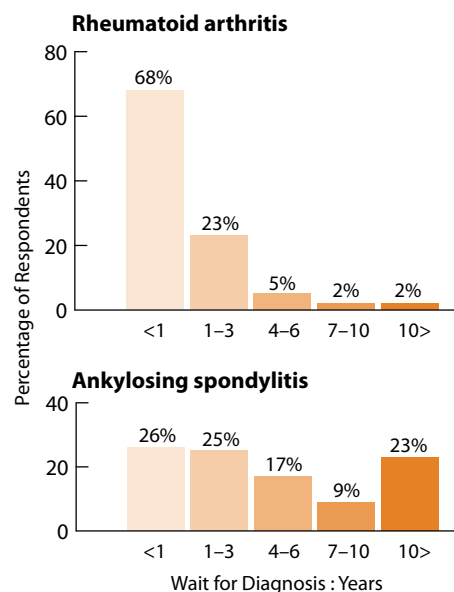
For respondents living with osteoarthritis, 57% received a diagnosis within less than one year. 22% were diagnosed between 1-3 years, 13% between 4-6 years and the remaining 9% waiting between 7 and 10 years.

For respondents living with inflammatory types of arthritis, 57% received a diagnosis in less than one year and 20% in 1-3 years. While this may seem like an acceptable period of

time for diagnosis, it is important to look at the differences in diagnosis times between the types of inflammatory arthritis diseases as there are valuable findings that emerge.

For example, while we can see in the chart below that 58% of people living with rheumatoid arthritis received their diagnosis in less than one year, only 26% of people living with ankylosing spondylitis and 38% of people with lupus were able to get a diagnosis in this time frame.

Even more troubling is the percentage of respondents who had to wait more than 10 years to be diagnosed with their disease, including 23% of people living with ankylosing spondylitis and 23% of people living with lupus. This stands in stark comparison to only 2% of those respondents living with rheumatoid arthritis.



The lengthy delays in getting a diagnosis for people living with ankylosing spondylitis and lupus are highly problematic because of the impact on accessing treatment and care. Research has proven that starting treatment for inflammatory arthritis in the early stage of disease onset is the best way to prevent irreversible joint damage. In fact, we now know that there is a small window of time, at the outset of the disease process, when proper treatment can actually prevent joint damage^{iv}.

Unfortunately, many people with arthritis in Canada are not receiving the best treatment possible. Recent research conducted by Dr. Diane Lacaille found that only 43 percent of the people diagnosed with rheumatoid arthritis in British Columbia received disease modifying anti-rheumatic drugs (DMARDs), a class of medications considered “essential” to preventing joint damage and controlling disease in the early going^v.

Diagnosis and the healthcare system

The issue of timely diagnoses has a significant impact on the lives of people living with arthritis in terms of managing their disease, and also has a considerable impact on the health care system. When we asked people how many health care professionals they saw before receiving their diagnosis, there were important differences between different arthritis disease groups.

The majority of respondents living with rheumatoid arthritis and osteoarthritis saw no more than two health care professionals to get a diagnosis, with only 25% and 20%, respectively, seeing more than three health care professionals.

In contrast, those respondents with psoriatic arthritis, ankylosing spondylitis and lupus were more likely to see three or more professionals before being diagnosed, 51%, 62% and 65%, respectively. In addition, for respondents with lupus and ankylosing spondylitis, 17% and 19% respectively saw more than 6 health care professionals before receiving a diagnosis.

The need to see more than three, and in some cases many more than six, health care professionals to receive a diagnosis negatively impacts the health of people living with arthritis and adds unnecessary costs to a health system already suffering from cost pressures.

Treatment options:

How Survey respondents currently manage their disease

The top three treatments, tools and therapies that respondents are currently using to treat their arthritis are:

Prescription medications **80%**

Vitamins/supplements **59%**

Exercise therapy **58%**

In addition to the top three, individuals also reported using self-management programs (27%), registered massage therapy (23%), physiotherapy (22%), house cleaning services (14%) and medicinal marijuana (3%).

The findings regarding treatment are similar to what research has shown that people living with arthritis use to manage their disease. While appropriate treatment with prescription medications is a key tool for people living with arthritis, in particular inflammatory arthritis, it is encouraging to see so many respondents say they use exercise. Research tells us that exercise is a key aspect of arthritis treatment. It helps to keep the muscles strong, protecting the joints and is also an important way to maintain a healthy body weight^{vi}. In addition to those benefits, exercise is beneficial for mental well-being and can be a good way to socialize with friends and family.

Gaps in arthritis treatment and care: Issues of cost and coverage

In addition to asking respondents what they currently use to manage their disease, an important aspect of this survey was to find out what treatments, tools, and therapies people with arthritis indicated they needed but were not receiving due to financial cost. The top five overall responses are:

Registered massage therapy **32%**

Exercise therapy **32%**

Vitamins/supplements **28%**

Non-prescription medications **24%**

House cleaning services **24%**

Physiotherapy **23%**

When we look at this data by disease groups, focusing on osteoarthritis, rheumatoid arthritis, ankylosing spondylitis and psoriatic arthritis, we see that with the exception of respondents with ankylosing spondylitis who listed massage therapy as something they need but are not receiving due to cost (31.7%), exercise therapy was the top answer for these respondents. This is an important finding and one that needs to be addressed by policy makers, health care providers and people living with arthritis. As exercise is central to managing arthritis diseases, barriers to exercise—such as cost—need to be removed.

In addition to the top five treatments, tools and therapies people reported needing but not receiving due to cost, 19% of respondents indicated not receiving their needed prescription medications due to cost. This is an alarming finding because research has shown that appropriate treatment of certain types of arthritis with prescription medications are one of the most important methods to managing the pain, joint destruction and disability of arthritis^{vii}.

As well, this finding sheds light on the problems that exist in provincial and territorial drug plan reimbursement programs. On further inspection, important geographic differences emerge. For example, 20.9% of people with rheumatoid arthritis in BC responded that they need prescription meds that they are not currently receiving due to cost. This compares with only 7.7% of Ontario respondents with rheumatoid arthritis.

Similar findings appear in respondents living with psoriatic arthritis and ankylosing spondylitis. In British Columbia, 27.3% respondents with psoriatic arthritis are not currently receiving prescription meds they need due to cost and 22.2% of people with ankylosing spondylitis need prescription meds that they are not currently receiving due to cost. While we can only speculate, one of the reasons for these findings may be related to the differences in medication coverage across Canada.

As we noted in our 2007 September/October issue of JointHealth™ monthly, formulary reimbursement listings for arthritis medications vary widely across the country. For example, people living in Manitoba with ankylosing

spondylitis have no access to provincial reimbursement for biologic response modifiers; people in Ontario with the same disease have financial coverage from the province for two biologic medications.

Treatment priorities: in your perfect world

Respondents were asked to indicate their priorities in terms of which tools, therapies and treatments they want to have reimbursed 100%. The top four first priorities that people listed include:

Prescription medications **78%**

Physiotherapy **36%**

Health services insurance **36%**

Exercise therapy **30%**

Some final thoughts

Far too often, the voices of people living with disease are not included in research. Yet, we know that patients' voices and experiences provide a unique and important contribution to the body of knowledge on arthritis. That is why Arthritis Consumer Experts is committed to gathering your views through surveys such as the one reported above.

Thank you to everyone who participated in the JointHealth™ Survey on Arthritis Treatment and Care. Your participation helped to ensure that the voices of people with arthritis are heard by researchers and health policy decision-makers.

Links to internet sites with credible research information:

www.arthritisconsumerexperts.org

www.arthritisresearch.ca

<http://www.nlm.nih.gov/hinfo.html>

<http://www.cihr-irsc.gc.ca/e/193.html>

If you have any questions or comments on these findings, please provide feedback to JointHealth™ monthly at info@arthritisconsumerexperts.org.

Arthritis Consumer Experts and ACE Planning and Consulting Inc. encourage the use and dissemination of the information in this document. Please kindly cite the source of the information you or your organization uses from it. Thank you.

i Finckh et al., 2006: 864; Suter et al., 2004: 300;
 ii Lacaille et al., 2005; Yelin et al., 2007; Suter et al., 2006; Kasman and Badley, 2004: 1;
 iii Ozbek et al., 2003; Feldman et al., 2006; Bernatsky et al. 2006; Suter, et al., 2004; Lacaille et al., 2005.
 iv Lacaille et al. 2005
 v ibid
 vi Andersen et al., 1997; Bruce et al., 2005
 vii Van der Heijde et al., 2006; Lambert et al., 2007; Heiberg et al., 2008

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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