



Living with Rheumatoid Arthritis: Unmet Needs

In 1998 it was estimated that in the United States alone nearly one percent of the population, approximately 2.1 million people, had rheumatoid arthritis¹. Rheumatoid arthritis (RA) is one of the most common and serious forms of arthritis. It is characterized by inflammation of the synovium - the membrane lining the joint, which causes pain, stiffness, warmth, redness and swelling. The inflamed synovium can invade and damage bone and cartilage, leading to joint deformities, loss of joint movement, and limitations of activities requiring use of joints. The disease usually begins in middle age, but can start at any age including during childhood. It affects two to three times more women than men.

The etiology of rheumatoid arthritis is not yet known. In RA, cells of the immune system called lymphocytes gather in the synovium causing inflammation and subsequent joint damage. Current scientific evidence indicates that a factor produced by the immune system, tumor necrosis factor (TNF), plays a critical role in the inflammation and, in particular, the joint damage that develops in RA. Genetic factors also are considered to play a key role in the development of the disease.

The goals of treatment of rheumatoid arthritis include reducing joint swelling, alleviating pain, relieving stiffness, preventing joint damage, and maintaining normal joint function. Aspirin-like drugs called nonsteroidal anti-inflammatory drugs (NSAIDs and Cox-2s) and corticosteroids (prednisone) help reduce joint pain, stiffness and swelling. Drugs referred to as disease-modifying anti-rheumatic drugs (DMARDs) include methotrexate, hydroxychloroquine, azulfidine, leflunomide and gold salts. These drugs work slowly to retard or stop disease progression. A

¹ Lawrence, R.C.; Helmick, C.G.; Arnett, F.C.; Deyo, R.A.; Felson, D.T.; Giannini, E.H.; Heyse, S.P.; Hirsch, R.; Hochberg, M.C.; Hunder, G.G.; Liang, M.H.; Pillemer, S.R.; Steen, V.D.; and Wolfe, F. (1998) Estimates of the Prevalence of Arthritis and Selected Musculoskeletal Disorders in the United States. *Arthritis and Rheumatism*, 41(5): 778-799.

new class of drugs called biologic response modifiers (BRMs) work to improve outcomes of RA by inhibiting a chemical called tumor necrosis factor (TNF), which the body produces as a part of the normal immune response to infection and include adalimumab, etanercept, infliximab and anakinra. In addition, treatment most often includes some combination of exercise, rest, joint protection, use of local heat or cold to reduce pain and physical and occupational therapy. Regular exercise combined with medications can help keep joints in working order and limit disability from the disease. It also may help prevent further joint damage. Surgery is available to relieve pain and improve function of damaged joints.

Survey Rationale

The purpose of this survey was to assess the current status of rheumatoid arthritis patients with particular attention paid to lifestyle and unmet needs despite recent medical advances.

Methodology

The telephone survey with 500 rheumatoid arthritis patients (aged 18 years and over) was conducted between August 9 and August 30, 2004 among a sample of self-identified rheumatoid arthritis sufferers in the United States compiled by Survey Sampling, International LLC.

Respondents were eligible if they had been told by a physician that they have rheumatoid arthritis, visited a doctor who specialized in arthritis at least once per year, and described their rheumatoid arthritis as moderate or severe. Further, respondents were either currently on a biologic medication (etanercept, adalimumab, anakinra, infliximab, n= 300) or one of two DMARD medications (leflunomide or methotrexate, n= 200). Respondents who had completely stopped taking a biologic medication within the three months prior to the survey were also eligible to participate. Based on market share estimates, the total sample was weighted to reflect the composition of rheumatoid arthritis patients who take these biologics or DMARDs. In theory, one can say with 95% certainty that the results have a statistical precision of plus or minus 5 percentage points of what they would be if the entire group of patients who are using the biologic

(etanercept, adalimumab, anakinra, infliximab) or DMARD (leflunomide or methotrexate) medications had been polled with complete accuracy.

Survey Parameters

Survey respondents were asked a series of questions under the topic headings of rheumatoid arthritis impact and assessment, hopes and fears about their future with the disease, medication usage, benefits and expectations, rheumatoid arthritis resources and sources of information and demographics.

Results

Regarding current quality of life with the disease, survey respondents were asked a series of questions about their RA symptoms. The majority of patients taking either biologics or DMARDs report that their medication has helped them to some degree with symptom relief. However, among the number of respondents using biologics, 75 percent still experience daily stiffness, 67 percent experience daily fatigue, 71 percent experience daily pain, 48 percent experience daily swelling in the joints and 55 percent experience having to modify household activities on a daily basis. Of those respondents currently taking DMARDs, 69 percent still experience daily stiffness, 67 percent experience daily fatigue, 70 percent experience daily pain, 41 percent experience daily swelling in the joints and 47 percent experience having to modify household activities on a daily basis.

Respondents were also asked a series of questions directly related to the effect that rheumatoid arthritis has on various aspects of their lives. Using a 10-point numerical scale (where 10 means completely prevents participation in that activity and 1 means no effect on participation in that activity), 65 percent of those taking biologics and 61 percent of those taking DMARDs rated their ability to do everyday tasks at 5 or higher, 58 percent for biologics and 53 percent for DMARDs

rated their ability to maintain a healthy weight at 5 or higher, and their ability to participate in physical activity at 5 or higher, 74 percent and 66 percent respectively. Thus more than half of all respondents in both treatment categories continue to experience clinically significant activity and lifestyle limitations.

Overall quality of life ratings reflecting the prior six months were recorded by respondents using a 10-point numerical rating scale, where 10 means highest quality of life and 1 means lowest quality of life. Forty percent of those taking biologics and 39 percent taking DMARDs rated their overall quality of life at a 5 or below.

Respondents were asked a series of questions related to their hopes and fears about the future with their disease. When asked how concerned they were that in the future various negative effects would happen due to their disease, 60 percent of those taking biologics and 51 percent of those taking DMARDs were either very concerned or extremely concerned that they would become disabled. Fifty-four percent of those taking biologics and 42 percent of those taking DMARDs were either very concerned or extremely concerned that they would become deformed with 56 percent of those using biologics and 53 percent of those using DMARDs were either very concerned or extremely concerned that they would not be able to care for themselves. Lastly, 57 percent of respondents using biologics and 51 percent of respondents using DMARDs were either very concerned or extremely concerned that they won't be able to participate in their favorite hobbies and activities.

Medication Usage

Using a 4-point Likert scale, participants rated their level of concern about potential consequences of their RA medication use. The development of potential long-term negative consequences to their health was the most significant concern for both biologic and DMARD-treated patients with 45 percent and 41 percent respectively being very or extremely concerned.

Forty-two percent of biologic users and 36 percent of DMARD users were very or extremely concerned about the increased risk of infection while 33 percent of those taking biologics and 34 percent taking DMARDs were very or extremely concerned their medication did not relieve fatigue well enough.

Survey respondents were asked about a list of 9 benefits that might be important to them when considering a new arthritis treatment. For those treated with biologics, most important was the medications ability to relieve pain more completely, followed by providing longer periods of relief from painful symptoms and thirdly having fewer side effects. For those treated with DMARDs, relieving pain more completely topped the listing, followed by having fewer side effects and lastly providing longer periods of relief from painful symptoms.

Arthritis Resources and Sources of Information

Respondents were asked to rate the trustworthiness of 11 sources of information including their doctor, pharmacist, a family member or friend, health insurance companies, pharmaceutical companies, news media, advertisements (television or other), Internet sites, *Arthritis Today* Magazine (publication by the Arthritis Foundation), non-profit organizations and the Arthritis Foundation. Using a scale from 1 to 10 where 10 means extremely trustworthy and 1 means not at all trustworthy majorities of respondents gave the following sources a rating of 8 or higher when evaluating the trustworthiness of each of them: their doctor (86%), their pharmacist (80%), and the Arthritis Foundation (72%) *Arthritis Today* was found the fourth most trustworthy with 65 percent of respondents giving the magazine a rating of 8 or higher.

Conclusion

Recent medical advances in the treatment of rheumatoid arthritis have undoubtedly contributed to improved outcomes for patients living with RA. However this survey demonstrates that notwithstanding, RA patients continue to endure significant symptoms, experience compromise of

their daily activities and quality of life and live with RA-related concerns. Therefore the rheumatology scientific community is obliged to continue diligent and aggressive research in pursuit of superior treatments that will meet the unmet needs of the RA population.

For the patient with rheumatoid arthritis - working with a team of appropriate healthcare providers to acquire an early and accurate diagnosis and an aggressive treatment plan can make a significant difference in the course of the disease. An effective treatment plan should include medication and a combination of exercise, rest, joint protection, use of local heat or cold to reduce pain and physical and occupational therapy. In addition, the rheumatoid arthritis patient can benefit greatly from open and frequent communication with healthcare providers, staying current with the latest information about the disease and new treatment options and incorporating elements of mind, body and spirit for a more complete treatment plan.

National resources and local services are available to help individuals live a greater quality of life with RA. Contact the Arthritis Foundation and ask about the Arthritis Self-Help Course, People with Arthritis Can Exercise (PACE), aquatics classes, [Good Living with Rheumatoid Arthritis](#) published by the Arthritis Foundation, as well as our popular online community for people with RA known as *RA Connect*.

The Arthritis Foundation is the only nationwide nonprofit health organization helping people take great control of arthritis by leading efforts to prevent, control and cure arthritis and related diseases. The Arthritis Foundation is the only national non-for-profit organization that supports the more than 100 types of arthritis and related conditions with advocacy, programs, services and research. For more information about rheumatoid arthritis, please contact the Arthritis Foundation at 1.800.283.7800 or by visiting our website at www.arthritis.org.

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