

Awareness of Rheumatoid Arthritis (RA) Has a Great Impact on Patients

Kelly Young

Kelly is an empowered patient who blogs and tweets on Rheumatoid Arthritis (RA) and advocates for RA and other incurable diseases. She is on the Mayo Clinic's Center for Social Media Advisory Board and has been a guest at RA medical conferences as more physician groups open up to the presence and input of patients. Her RA website can be found at <http://rawarrior.com>. Her Twitter name: RAWarrior

In the last few months, Mayo Clinic researchers have ascertained for the first time that the lifetime risk of being diagnosed with some kind of inflammatory autoimmune arthritis (mostly RA) is 8.4 percent for women and 5.1 percent for men. Project spokesperson, Cynthia Crowson, points out in a short video that she deems the total risk for women to be comparable to that of breast cancer. The key point to Mayo's recent press release was that they hope the new information can be used to raise awareness. [See video and further discussion at this link.](#)

RA Patients have unique needs

Of course we all want to *need* as little healthcare as possible. No one expects to become chronically ill and spend a great deal of his time and livelihood in the healthcare system. However, this is what most people diagnosed with RA (or one of the similar autoimmune diseases) do.

Often, we spend as much time with medical professionals as we do with friends, neighbors, or our church family. Like it or not, we become dependent upon the skill and care of these strangers. Their treatment of us makes a significant impact on our lives.

The term Rheumatoid Arthritis may lead one to believe that RA patients merely contend with achy joints. However, RA can attack any organ or body system and create severe disability. RA patients often manage several secondary conditions, including heart and eye disease. Typically, they see several types of specialists and have frequent lab work and imaging studies, having more total healthcare encounters than most families combined. I've had more healthcare encounters in the past five years with RA than in the rest of my life, even though I have five children and other diagnoses. Most people are familiar with the management of Type 1 Diabetes, so I sometimes explain living with RA as similar to that in part.

When an RA patient has a healthcare appointment, one of two things happens. If the medical staff has a basic understanding of RA, there is gentle or even sympathetic delivery of whatever test or therapy is required. But if that basic understanding is lacking, there can be unnecessary discomfort or conflict.

RA patients are so dependent upon the healthcare system that I frequently hear stories from them about their experiences. A greater awareness about RA could bring understanding that inadvertent tugging and twisting joints too forcefully can create painful flares. Requiring an RA patient to hold a heavy clipboard or keep her arms extended during a mammogram may not be realistic. Telling a patient that "arthritis" shouldn't hurt so much can ruin rapport.

These typical examples illustrate how much of a difference RA awareness could make. RA is a leading crippling disease and one of the most painful medical conditions. There is no cure and remissions are rare. A [survey of 27,000](#) patients published last year showed that 72% live with daily pain despite disease treatment and pain medications. Yet, patients and experts agree that RA is frequently misunderstood. Professor Rebecca Bader, fellow of the Burton Blatt Institute at Syracuse University says, "I'm astonished by how little people know about RA."

Healthcare workers could improve the lives of people with RA

Whether it's providing steady support instead of pulling a patient up onto a scale or cheerfully moving a blood pressure cuff off of a joint, there are many simple ways that the care of RA patients could be improved. Since 68% of RA patients say that they feel the need to conceal their pain, it may not always be obvious what assistance is needed. Perhaps it seems easier concealing pain than asking for help from someone who doesn't understand. My hope is that we could begin to break this cycle of unawareness about the harsh symptoms of RA and the needs of patients.