

VIEWS & REVIEWS

PERSONAL VIEW

Doctors' understanding of rheumatoid disease does not align with patients' experiences

The patient activist **Kelly Young**, a self described rheumatoid arthritis warrior, wants to change this

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When I was diagnosed as having rheumatoid arthritis in 2006, I knew nothing of its symptoms or treatments. I had no concept of typical disease presentation or what the medical profession thought about it. I had not heard of DMARDs (disease modifying antirheumatic drugs), cytokine, or DIP (distal interphalangeal) joints.

Weekly injections of adalimumab and 25 mg of methotrexate effectively reduced fatigue and symptoms of vasculitis, but daily fevers and constant joint inflammation continued, leaving me unable to accomplish most of my usual tasks. After two and a half years, my sympathetic rheumatologist confessed to not knowing what else to prescribe. Then I read everything I could.

Passing time brought more functional loss. While I mourned my old life I was determined not to surrender to a perpetual downward slide. I would fight this disease in whatever way I could find.¹ I devoured academic articles, news stories, and patients' reports, recording what I learnt in a blog called RA Warrior (<http://rawarrior.com>).

Usual explanations of rheumatoid arthritis had led me to think that I had atypical presentation of the disease and response to treatment. So I concentrated on the experiences of others. Months later I became convinced that, although I might be in a minority, I was not unique, and eventually I dared to write about my experiences. For example, hands were neither the first involved joints, nor the worst involved joints; disease activity was stable, without flaring; swelling did not correlate with other symptoms; neck joints were involved; and symptoms were not alleviated by treatment.

People responded in large numbers, and I was often surprised to discover how many deviated from what was said to be the norm. Comments on websites and social media are not scientific sampling, but the number was large enough that I began to question conventional assumptions. By mid-2012, 21 500 had become fans of our Facebook page, exceeding 1% of all patients with rheumatoid disease in the United States. In 2013, it will reach 2%.

In 2011 and 2012 we conducted surveys that confirmed what patients had been saying in the past few years.² We found that stiffness was limited to mornings in only a quarter of patients; most people undergo protracted diagnosis; swelling is not usually correlated with damage; few people experience sustained remission; and the vast majority experience fevers, correlated with fatigue.

Regarding disease activity and responses to treatment, our population mirrored large samples such as those described by Wolfe,³ Strand,⁴ and others.⁵ I often noted academic sources that confirmed our findings. Examples of inconsistencies between patients' experiences and clinicians' perceptions included clinicians thinking that DIP joints are not affected,⁶ that swelling distinguishes disease activity,² that spinal joints are often not involved,⁷ that small joints are affected first,⁸ and that most patients have an exceptional response to treatment.⁵⁻⁹

Over the years my audience grew and I was grateful to participate in many events representing people with rheumatoid disease.¹⁰ People often asked when the RA Foundation would improve the lot of patients with the disease. But there was no such organisation in the United States. Early in 2011 we remedied that by creating the non-profit making Rheumatoid Patient Foundation.

Reviewing history and current investigations with great interest, the foundation has begun to consider patients' concerns. We have identified the fundamentals of care¹¹ and initiated a return to the term "rheumatoid disease" because it is impractical to label a systemic disease by one of its symptoms: arthritis.

In 2013 we established rheumatoid awareness day, on 2 February. Thankful for partnership with supportive professionals, we work on education, research, and advocacy.¹² Being patients ourselves makes the work challenging but also adds resolve and clarity to our mission.

I often receive inquiries from patients whose doctors assert that they are mistaken about symptoms. When doctors question involvement of the jaw joint, I recall a poster session on

researching a topical steroid for jaw inflammation. When doctors dismiss spinal joints, I recall many friends who needed spinal surgery or a woman who died because she did not have surgery. Many such examples compel me to ensure that doctors understand the reports of their patients with rheumatoid disease.

Comprehending the patient experience is essential to improving care, and this experience often differs from what textbooks lead clinicians to believe. Several clinicians with rheumatoid disease have submitted comments to my blog, such as, “I am a physician with RA. I have been so let down by my profession . . . Feeling like I have to prove how awful I feel fills me with self doubt. You can’t measure pain. That’s not the worst part; daily fevers and 25 pound weight loss have left me barely functional. But I’m seronegative and apparently doing just great! I used to run 10k. I walked around for 2 years with two ruptured discs in my spine before finally having surgery. I am no stranger to pain. I have kept trucking through it all. The only thing I want is my life back. Not pity. Not attention. Not pain meds. You are leading a trail of awareness letting patients know that it’s ok to stand up for their needs and rights and hopefully our rheumatologists will be re-educated as well.”

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