How Spondyloarthritis Affects Quality Of Life

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How much does spondyloarthritis affect one’s quality of life?
I recently had the honor to present posters addressing this question at the EULAR (European League Against Rheumatism) meeting in Amsterdam, as well as at the American College of Rheumatology meeting in Chicago. The presented studies represented a collaboration with Lisa Pisenti of UCB and Gina Park of Novartis along with Richard Howard of the SAA. UCB and Novartis are pharmaceutical companies that make medications that could benefit patients with spondyloarthritis (SpA.)

Why did we do these studies?
There are many ways to assess the severity of spondyloarthritis. Many readers have undoubtedly completed a BASDAI questionnaire on a visit to their rheumatologist. BASDAI stands for the Bath (England) Ankylosing Spondylitis Disease Activity Index. It collects information on issues like pain, sleep, and morning stiffness to create a disease activity score. We can also assess the extent of the disease with x-rays of the spine or joints like the hip. Doctors take measurements such as how much can the neck rotate, the chest expand, or the back flex to monitor disease activity. And sometimes your doctor will do a blood test, usually a CRP (C-reactive protein) to gauge the activity of your inflammation. But arguably the most important information is how you as the patient perceive the illness. How does it affect your day-to-day life such as your work, your relationship to your family, your major life decisions? A director wants to make a movie that will please audiences; a physician wants to make a recommendation, or prescribe medication that will make a difference to a patient and their lifestyle. Finding out what is meaningful to our patients is the first step towards that goal.

How did we do these studies?
We randomly selected participants from within SAA’s engaged membership and community.

Patients were invited to respond to a series of questions designed to learn about their disease, the treatments they were receiving, and how the illness was affecting their life. Because patients sometimes respond differently to a phone interview in comparison to an online survey, patients were recruited and the survey administered through telephone calls as well as online. In all, more than 800 patients participated in the study, each having reported that they were diagnosed with spondyloarthritis by their doctor. As our goal was 800 complete responses, we closed the survey once we confirmed the completed numbers.

What did we learn?
The survey produced a wealth of information. On average, it took over eight years from the time that symptoms began until the disease was diagnosed. This shows that there is a huge opportunity to educate the public about the illness as well as an opportunity to educate physicians to recognize SpA more readily.

We found that by almost every measure, women were more impacted by this disease than men. The explanation for this is complex and certainly not immediately obvious. In the United States, women live longer than men and also visit the doctor more than men. An obvious possible explanation is that the disease is simply more severe in women than men, although using a measurement like the CRP would not necessarily support that idea. Women might perceive pain differently from men. Perhaps it is culturally more expected that men should be stoic, but if this is true, many women are obvious exceptions to this.

OTHER NOTABLE DIFFERENCES IN WOMEN & MEN WITH SPA:

<table>
<thead>
<tr>
<th>Condition</th>
<th>Women (%)</th>
<th>Men (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>High blood pressure</td>
<td>42.7%</td>
<td>28.5%</td>
</tr>
<tr>
<td>Heart disease</td>
<td>14.0%</td>
<td>4.0%</td>
</tr>
<tr>
<td>Fibromyalgia</td>
<td>4.2%</td>
<td>22.1%</td>
</tr>
</tbody>
</table>
We also learned that a majority use non-medicinal approaches to SpA. For example, stretching and strengthening exercises are very common, and over a third of participants (39.4%) followed special diets at time of being surveyed. We learned that it is not uncommon to try narcotics for the pain. And 8% were either taking or had tried medical marijuana. As expected, patients were taking a variety of medications, and it was clear that many medications had been tried and then abandoned for another alternative.

About three quarters of the respondents were (completely to somewhat) satisfied with their treatment. This is encouraging but it also means that up to one in four are not happy with treatment. And finally, for about 25% of patients, SpA clearly had a major impact on vital activities like choice of career or time spent with friends or family.

**Satisfaction with Treatment Among Respondents with SPA**

<table>
<thead>
<tr>
<th>Satisfaction Level</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unsere / not available</td>
<td>7.8%</td>
</tr>
<tr>
<td>Not Satisfied</td>
<td>7.2%</td>
</tr>
<tr>
<td>Slightly Satisfied</td>
<td>8.9%</td>
</tr>
<tr>
<td>Somewhat Satisfied</td>
<td>21.7%</td>
</tr>
<tr>
<td>Mostly Satisfied</td>
<td>38.9%</td>
</tr>
<tr>
<td>Completely Satisfied</td>
<td>15.5%</td>
</tr>
</tbody>
</table>

Why are these studies important?

A survey like this provides critical information. For example, documenting that 25% of patients are unable to pursue a preferred career because of their inflammatory disease means that there exists an unmet need to improve how we treat this condition. The long delay from onset of symptoms to diagnosis might markedly affect how successful treatment is. In rheumatoid arthritis, it is clear that there is a window of opportunity early in the disease process, and that this opportunity is lost as the disease progresses. We suspect that the same is true for ankylosing spondylitis; proving this supposition, however, is difficult.

One of the most important aspects to a survey like this is its utility to persuade funding sources, like the National Institutes of Health or pharmaceutical companies, to support future SpA research. Unfortunately, the federal government has limited resources to spend on medical research and there is constant competition for those dollars. Patients need to be advocates for increased research on their diseases, and we as researchers need to arm these advocates with data to persuade government leaders that more can, and should be done.

Can we have confidence in our data?

I suspect that very few novelists complete a story and announce: “It’s a masterpiece, absolutely perfect.” Medical researchers should also be aware of the limits of their work. Most importantly, we can’t say for sure that those who responded to the survey are representative of everyone with spondyloarthritis. Maybe those with mild disease are less likely to be aware of the disease. Or perhaps those with severe disease are less likely to spend time using a computer. For unknown reasons, women are more likely than men to participate in a survey like this.

Despite these possible shortcomings, the study documents how significantly this illness can impact one’s life. As recently as the 1960s, many physicians believed that AS was just a variant form of rheumatoid arthritis. We have come a long way in diagnosing and treating spondyloarthritis, and we still have a long way to go.

- Spondyloarthritis is associated with a number of manifestations and related conditions, including **uveitis, inflammatory bowel disease, psoriasis, cardiovascular diseases, diabetes, osteoporosis, and depression**. Other notable conditions reported by survey participants include:

  - Acid reflux (50.7%)
  - Eye inflammation (45.2%)
  - High blood pressure (34.3%)
  - Irritable bowel syndrome (34.3%)
  - Balance issues (31.5%)
  - Migraine (31.5%)
  - Depression (23%)

- The three most commonly reported locations of pain in this survey population were the **low back** (86.5%), **neck** (82.4%), and **hip joint** (79.9%).

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