

INVESTIGATING QUALITY OF LIFE IN VETERANS WITH ANKYLOSING SPONDYLITIS

Editor's Note: Below is an excerpt from "Investigating Quality of Life in Veterans with Ankylosing Spondylitis" a thesis paper by Kyle W. West, who recently received his Master of Science Degree at University of North Texas. His paper was prepared for the Department of Veterans Affairs North Texas Health Care System, Department of Rheumatology, under the guidance of Kara Prescott, MD.

We wanted to share with you, our readers, the final section of the paper: His discussion and personal thoughts. We have also added quotes from veterans with AS he interviewed on the following page.

Before being tasked with this subject matter, I had never heard of ankylosing spondylitis. In fact, it was more than a week of assiduously repeating the name before I was able to

enunciate it without tongue-tripping over the word. In spite of this complete unfamiliarity, I learned a great deal about AS. I began my preliminary research by familiarizing myself with the disease – its symptoms, progression, and treatments. My initial assumptions were that those with longer disease duration and higher disease activity would have a lower opinion of their quality of life. However, this is not necessarily the case. I found that there is a myriad of influences on how a patient feels about his life. In fact, the only data that supported my initial assumptions is that the majority of patients reported that their military experiences have strengthened them mentally and helped them to cope with their disease.

The patients interviewed during this study were still military men, despite the fact that their fighting days are long past. As the main character of the 2009 film *Avatar* (a disabled marine) says, "You may be out, but you never lose the attitude." This attitude can serve to both help and hurt those suffering from AS. The benefits could include being more likely to follow doctors' orders as they are accustomed acquiescing to perceived authority figures and giving the patients the mental toughness to cope with the disease. However, continued military identification could hurt them by making them more reluctant to accept help when it is needed, increasing the likelihood of depression when they must rely on others. It can also serve as an obstacle to seeking proper care in a timely manner due to the "suck it up" attitude fostered by military service. This causes many to try to simply struggle against the pain.

Given the small population interviewed, very few concrete findings are to be taken from this study. However, the data gathered have allowed recommendations for the rheumatology clinicians to be made in order that they maintain their present high level of patient satisfaction. This study has also shown how medical anthropology can help resolve issues of patient non-compliance in the rheumatology department of the Dallas VA. If more detailed ethnographic investigation is employed, patient satisfaction would likely increase. Also, given the large number of medical residents that serve in the rheumatology clinic, there is a unique opportunity to expose these newly minted medical practitioners to the value of a "clinical social science." By learning how to understand the difference between illness and disease and how to respond appropriately to both, the high quality of patient care in the Rheumatology Department can be spread as the residents move into other departments and into practice elsewhere.



It started when I was a teenager in the military and they tried to connect it to the environment because I worked down in the engine room with asbestos, lead, mercury, all those nasty things and they don't give you no respirator or nothing. I just always thought it was related.

– AS sufferer for 42 years

They shoved us through the medical processing and I remember I got a vaccine for anthrax in one arm and God knows what else and then, within 24 hours – 48 at the most – I felt what I thought was a pulled muscle in my butt. I really think that it was those vaccines that started it.

– AS sufferer for four years

It was after an accident in the army when I was bounced out of the back of a truck. That's the first time I ever noticed any back pain and it hasn't cleared. One doctor told me that it may have activated the HLA-B27 gene. It's active now, that's for sure!

– AS sufferer for 25 years

I was in a car accident where I was rear-ended. Then all of a sudden, it got really bad. I guess that was about 2002 or 2003.

– AS sufferer for seven years

You come into this building and you think you're having a bad day and you look around here and you say, "Boy, I'm glad I've got what I've got." Coming to the VA is healthy, I think, at times.

– AS sufferer for 10 years

You have to learn coping skills in the military; you don't have a choice. Here, I've got that same problem – I'm going to have to cope with it for the rest of my life.

– AS sufferer for 15 years

I have pain, but I can deal with it and it doesn't bother me that much and I think that goes back to the army.

– AS sufferer for 46 years

I don't go out anymore because it hurts too much. My social life sucks.

– AS sufferer for five years

I don't have social relationships.

– AS sufferer for 15 years

I have friends, but it's a burden on them to take me any place.

– AS sufferer for five years

I've become something of a recluse now.

– AS sufferer for 53 years

I'd have to say yes. It's not that I'm highly dependent on her, but she understands my predicament.

– AS sufferer for 10 years (when asked if disease has strengthened relationship)

My daughter helps me out a lot. We've been closer.

– AS sufferer for 36 years

We've really grown closer together.

– AS sufferer for 42 years speaking of his marriage post-AS

Before I got on the [TNF-a Inhibitor], I was absolutely depressed. I was pissed off at the world, pissed off at everything. I just didn't enjoy anything because every day was just pain. [The medication] has changed everything.

– AS sufferer for four years

I take [the medication] and I feel good. Every day, it's doing me good.

– AS sufferer for 20 years

[The medication is] great. I guess it's helped stop my arthritis. It's the best medication that I've taken so far.

– AS sufferer for nine years

I love the [TNF-a Inhibitor]!

