Introduction

Ankylosing Spondylitis: A Dual Perspective of Current Issues and Challenges

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ABSTRACT. This series of articles on ankylosing spondylitis (AS) provides insight into the burden of disease and focuses on early diagnosis and effective management. AS leads to progressive functional impairment over time and has tremendous impact on society at large in terms of economic costs and indirect costs associated with physical impairment and loss of employment. Early diagnosis is crucial now that we have more effective therapy with tumor necrosis factor (TNF) antagonists, which suppress disease activity and improve the functional ability of patients whose disease is refractory to conventional drug therapy. Early identification of variables that help predict severe disease with bad functional prognosis is needed. If biological therapy with TNF inhibitors is proven to retard disease progression and prevent or delay functional limitations, insight into such prognosticators will help us offer the correct treatment to the correct patient at the correct time. There is also a need to demonstrate longterm benefits of such a therapy as well as a favorable cost/benefit ratio to help convince healthcare authorities, insurance companies, and others of the utility of these drugs for treating patients with AS refractory to conventional drug therapy. (J Rheumatol 2006;33 Suppl 78:1-3)

Key Indexing Terms:
ANKYLOSING SPONDYLITIS DIAGNOSIS TREATMENT

This series of articles on ankylosing spondylitis (AS) provides insight into the burden of disease and focuses on early diagnosis and effective management. AS is a chronic systemic inflammatory rheumatic disorder of uncertain etiology with a predilection for the axial skeleton[1,2], which can lead to progressive bony fusion of the vertebral column; some patients may also show involvement of the hip and/or shoulder, and less often, peripheral joints. Extraarticular structures may also be affected such as the eyes, heart, and lungs[1-5].

This article has been written from a dual perspective: I have been a patient with AS for the last 50 years; and AS has been the main focus of my academic pursuit as a rheumatologist[1-3,6-19]. I do not mind sharing with the readers some of the many hurdles I have faced as a patient, in order to bring awareness to the medical community at large about some of the many challenges faced by patients with AS.

My disease was not diagnosed for 6 years, and I received many inappropriate treatments during that time, including prolonged bed rest and a year of antituberculosis therapy. I was even given a short course of honey by intravenous infusions that did not affect my disease, but I am sure it has left me ever so sweet.

Sadly, the delay in diagnosis I experienced is not atypical, and the situation has not much improved over the years[17]. Early diagnosis is very crucial now that we have much more effective therapy. Elsewhere in this series, my colleague Dr. Elyan and I discuss how one can diagnose AS early[20] and with reasonable confidence, even before radiographs confirm the presence of definite sacroiliitis[13,16,18,19].

Patients with AS experience progressive functional impairment over time, and many of them are unable to maintain the level of employment that they had prior to the onset of disease, as discussed in the article by Drs. Boonen and van der Linden[21] also in this series. Patients with AS have lower vitality and quality of life as compared with the general population, and the illness has tremendous effect on society at large in terms of economic costs and the indirect costs associated with physical impairment and loss of employment[22-25].

As a result of my disease, I have had bilateral total hip arthroplasties with a subsequent revision arthroplasty, recurrent episodes of acute anterior uveitis, and progressive limitation of spinal mobility and chest expansion. At one time, I fractured my cervical spine, and the fracture did not heal despite many months of neck immobilization by a halo with vest. This ultimately needed a surgical fusion and another 3 months of neck immobilization.

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My illness has resulted in a complete fusion of my whole spine, including the neck. I cannot even nod my head, and have to bend at my hip joints to give an impression of a nod. I have virtually no chest expansion. One can imagine what might happen to me if I were to fall or faint. In particular, if I were to have the misfortune of needing a cardiac resuscitation; the probability would be high that, inadvertently, my death would be hastened because of a possible neck fracture during intubation, or broken ribs during cardiac massage.

I have managed to continue to take care of my patients and also to follow my academic pursuits, although at times it has been an uphill task. But I can say that I have enjoyed every bit of my life, with all its hardships, hurdles, and dramatics. I am very grateful to modern medicine for keeping me going, and in some ways I should consider myself to be a "bionic man."

Exercise and nonsteroidal antiinflammatory drugs (NSAID) have been the mainstay of treatment of AS for more than 5 decades, but they are often ineffective and offer little hope in arresting the disease process or delaying the progression of the disease[26]. As reviewed by Dr. Daniel Clegg in this series[27], the advent of biological therapy with tumor necrosis factor (TNF) antagonists etanercept and infliximab is currently revolutionizing management of this disease. These drugs have shown marked efficacy in suppressing disease activity and improving the functional ability of patients with disease refractory to conventional drug therapy with NSAID, although as yet, too little is known about their longterm effects.

A high percentage of patients with AS may qualify for treatment with TNF antagonists[28]. Those with shorter disease duration treated with a biologic agent have a greater likelihood of achieving a significantly better clinical response to TNF antagonists than the ones with longer disease duration. This again emphasizes the need for early diagnosis[29]. Input from patients and their self-help organizations[30,31] should be sought in order to learn from the patients' perspectives: their definition of severe disease and their attitudes towards the different treatment options. Many patients with AS have left the medical system and rely on over-the-counter medication and non-pharmacologic interventions to alleviate their symptoms. Better education of healthcare providers and patients alike will help improve the early diagnosis and increase awareness of the new and much more effective therapeutic options.

Early identification is also needed of variables (prognosticators) that predict severe disease and a bad functional prognosis. If biological therapy with TNF inhibitors is proven to retard disease progression and prevent or delay functional limitations, insight into such prognosticators will help us offer the correct treatment to the correct patient at the correct time. Moreover, longterm benefits of such a therapy need to be demonstrated, as well as a favorable cost/benefit ratio (A. Boonen, personal communication). Such evidence will help convince healthcare authorities, insurance companies, and others of the utility of these drugs for treating patients with AS refractory to conventional drug therapy.

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