

REVIEW ARTICLES

Impact of Ankylosing Spondylitis on Patients' Work Status, Functional Disability and Quality of Life - A Review

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Abstract:

Ankylosing Spondylitis (AS) is a chronic inflammatory rheumatic disease principally affecting the axial skeleton. The disease can have a profound impact on life quality in terms of physical, social and psychological well-being. It has a great detrimental effect on our social and economic stability as the disease is more severe in men than in women. Work disability in AS patients is higher than expected in the general population for both male and female. Patients with AS may incur significant medical costs which accelerate steeply with increasing loss of function (BASFI) and disease activity (BASDAI). Patients with

more severe disease activity are at greater risk for developing functional disability. AS influences the subjective health of the affected person, especially the physical health related QoL. BASFI, BASDAI, BASG and pain are significantly associated with SF-36 physical and mental domains in patients with AS. Pain, fatigue and stiffness are the most commonly reported symptoms of these patients. Sleep disturbance, anxiety, depression and sexual dysfunction are other factors that significantly affect patients' quality of life.

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Introduction:

Ankylosing Spondylitis (AS) is a chronic inflammatory rheumatic disease principally affecting the axial skeleton and is a cause of structural and functional impairment in affected individuals.¹ Starting from an early adult age, the disease can have a profound impact on life quality in terms of physical, social and psychological well-being.² Prevalence estimates vary between 0.1% and 2% in different populations. The male and female ratio is around 2:1, and the disease initially manifests at the third decade.³ It has a great detrimental effect on our

social and economic stability as the disease is more severe in men than in women.⁴ Greater populations of our country that are earning money are male. AS primarily affects the spine and the pelvis, whereas, women tend to have more involvement of the knees, hips, wrists, ankles, and pelvis with less severe spinal involvement.⁴ Because of its insidious nature, the diagnosis is sometimes delayed until late stages of the disease. Until recently, treatment has been limited to non-steroidal anti-inflammatory drugs, some disease-modifying antirheumatic drugs (DMARDs) and physiotherapy, but the development of cytokine inhibitors that inhibit the activity of tumour necrosis factor is an important advancement in the treatment of AS involving the axial joint.⁵

It is widely accepted that the patients' perception of disease impact and the outcomes of health-care should be included in clinical trials and similar forms of evaluative study. This has resulted in a significant increase in the availability of patient-assessed health instruments which aim to measure aspects of health from the perspective of the patient.⁶ "Disability" in AS is often equated with functional impairment and is measured with the same questionnaires. Disability, however, encompasses more than loss of physical function alone. It is a multidimensional construct in

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which problems at the bodily, personal, and social level are united.⁷ Recently, the World Health Organization (WHO) has revised the International Classification of Impairments, Disabilities and Handicaps (ICIDH) towards a more biopsychosocial model-the International Classification of Functioning, Disability, and Health (ICF) - to comprehend human functioning at the bodily, personal, and social levels through WHODAS-2.^{7,8,9,10} Among others, indexes of activities of daily living (ADLs), the Functional Limitations Profile (FLP) and Functional Status Questionnaire (FSQ) can be mentioned also.¹⁰

Measuring the disease activity in AS patients have been aided by different measuring scales which helps clinicians in daily evaluation of the patients. Among the various scoring systems, the ASDAS is the newest and better option.¹¹ The Assessment in AS International Working Group (ASAS) preferred version is ASDAS-CRP, while ASDAS-ESR is an alternative. It combines five disease activity variables but results in single scoring which has better sensitivity to clinical changes.^{12,13} Other scoring systems includes; pain [intensity; visual analogue scale (VAS)], spinal stiffness/inflammation (morning stiffness duration; VAS), functional ability [Bath Ankylosing Spondylitis Functional Index (BASFI) or Dougados Functional Index (DFI), patient global assessment of health status (VAS; last week) and spinal mobility.^{14,15,16,17} Single items, such as those recommended by ASAS, may not allow patients to appropriately report the wide impact of disease or treatment, providing a limited reflection of health.¹⁸ The resulting summary judgment of health status limits measurement validity and score interpretation.^{18,19} Patient-assessed health instruments usually take the form of questionnaires containing multiple items, or questions, to reflect the broad nature of health status, disease or injury.^{6,18} These instruments aim to provide an accurate assessment of health or disease from the patient's perspective, which contribute to validity and score interpretation.^{6,8,1,19} AS is addressed in different reviews many times, but our focus is on its detrimental impact on work status, disability and quality of life. This review will make a good ground for those who intend to work with this very important and contemporary issue.

Methodology:

This Literature review was done through an extensive online search. The search engines commonly utilized were PUBMED, Medscape, Google, Rheumatology journal search etc. The key words were ankylosing spondylitis, work status, employment status, functional disability, quality of life, socioeconomic factors, psychosocial factors, economical burden etc. Most of the search enquired contents published at a range from January 1990 to January 2014. In some cases papers were collected from icddr, BSMMU, BIRDEM and BCPS library.

Discussion:

To provide the most effective management in the care of individuals with AS it is important to determine how the disease and treatment affect health from the patient's perspective. The application of patient-assessed health instruments has become increasingly important within the assessment of health-care and more specifically within rheumatology. Significant progress in the field has been made since the initial ASAS recommendations, which acknowledged that they could change following new research evidence.²⁰

Impact on work status:

The main social roles of young adulthood are those of worker, spouse/partner, and parent. Developing a chronic illness during young adulthood may affect one's ability, or one's perception of their ability, to fulfill these roles.³ Boonen et al. (2001) in a study of 529 patients with a paid job before diagnosis of AS, 5% had left the labour force within the first year after the diagnosis, 13% after 5 years, 21% after 10 years, 23% after 15 years, and 31% after 20 years.²¹ Age and sex adjusted risk for withdrawal was 3.1 (95% CI 2.5 to 3.7) times higher than in the general population. In patients with AS, determinants of withdrawal from work were older age at diagnosis, manual work, and coping strategies characterized by limiting or adapting activities. Patients with work disability at the time of the study were older, came from a lower social class, and were more likely to have total hip replacement, peripheral arthritis, or comorbidity. Moreover, they reported worse physical function (BAS-FI), experienced lower quality of life, and more often had extraspinous disease than those with a job.

In a study Roussou et al. (1997) worked to identify the socioeconomic status through occupation of a large cohort of patients with AS and to determine possible relationships between occupation and clinical variables.²² In their study 85% were in full employment at the time of the assessment compared to 15% who were unemployed.²² When 50 employed patients were compared to 50 unemployed cases, the latter had increased disease activity and lower psychosocial well being. Employed patients from the higher occupational group, had less disease activity, and lower pain and depression than patients from the lowest occupational group.²² Patients with longer duration, active and more severe disease (e.g., restricted spinal mobility), reduced physical functional capacity, older age, chronic pain, physically demanding job, lower level of education, lower socioeconomic levels, hip arthritis or replacement and presence of other illness are the risk factors for lower rates of employment.²³

In a Dutch study patients with a paid job lost 5.0% of work days as the result of having AS, accounting for a mean of 10.1 days of sick leave due to AS per patient per year in addition to the national average of 12.3 unspecified days of sick leave.²¹ There are indications that the risk relating to employment issues is reduced when the patient receives vocational counseling. After adjustment for age, labor force participation was decreased by 15.4% in male patients and 5.2% in female patients compared with the general Dutch population. Work disability (all causes) was 15.7% and 16.9% higher than expected in the general population for male and female patients respectively. In particular, the proportion of those with a partial work disability pension was increased.²¹ Work status and productivity cost differs in different population.²⁴

Financial Burden:

The costs of AS in USA and Europe fall within the range of costs as reported in RA. Worse physical function is an important predictor of total costs. From two CEA trials comparing group physical exercise or spa-exercise treatment with usual care, it was found that the benefits of (expensive) interventions can be reached at acceptable costs-effectiveness.²⁴ Patients with AS may incur significant medical costs that are often unexpected. Data from a study conducted in Denmark estimated additional costs to include.²³ A cost-effectiveness study

on spa-therapy in AS showed that the clinical benefits of (expensive) treatments can be reached within acceptable costs. All types of costs accelerate steeply with increasing loss of function (BASFI) and disease activity (BASDAI) in patients with AS, while utility decreases significantly. Treatments that control disease activity and maintain patients' function are likely to offset the high cost and low quality of life of severe disease. Ward, (2002) in his study showed that the functional disability was the most important predictor of high total costs.^{25,26} The likelihood of having high (>\$10,000) total costs increased by a factor of 3 with each 1-point increase in the Health Assessment Questionnaire disability index modified for the spondyloarthropathies (HAQ-S; range 0-3). Interventions that maintain or improve patients' functional ability will likely have the greatest potential to decrease the costs of AS.²⁶

Zhu et al. (2008) in a retrospective, non-randomized, cross-sectional study a cohort of 145 patients assessed the annual direct, indirect and total societal costs, quality of life (QoL) of AS in a Chinese population in Hong Kong and determine the cost determinants.²⁷ Annual total costs averaged USD 9120. Direct costs accounted for 38% of the total costs while indirect costs accounted for 62%. Costs of technical examinations represented the largest proportion of total cost. Functional impairment is the most important cost driver and treatments that reduce functional impairment may be effective to decrease the costs of AS and improve the patient's QoL, and ease the pressure on the healthcare system.²⁷

Functional Disability:

Functional disability measures the extent to which self-care activities, mobility, and performance of household tasks have been impacted by the diagnosis of ankylosing spondylitis. Many AS patients (up to 45% by some estimates) experience only mild functional/physical disability, affected mostly by limited mobility.²³ Ankylosing spondylitis patients with more severe disease activity (e.g., severe pain, stiffness, peripheral/hip arthritis) are at greater risk for developing functional disability. Physical therapy and, in some cases, hip replacement surgery or surgical correction of spinal kyphosis (abnormal curvature of the spine) can help improve functional disabilities in patients with greater disease activity.

Dagfinrud et al. (2004) studied 314 patients with AS and 2323 people from the general population where they showed both male and female with AS reported significantly impaired health on all scales of the SF-36.²⁸ Women reported significantly worse health on physical health domains. However, when calculating differences from the general population, numerically larger s-scores were found for men (except for physical role and vitality). The relative impact of AS seems to diminish with increasing age. In AS better health status was significantly associated with the higher educational level across all scales. Deviations from the general population on the non-physical health aspects were especially pronounced in patients with low education. They concluded that all key dimensions of health are affected by AS.

Ward et al. (2005) in their study showed that functional limitations in patients with AS for ≥ 20 years are greater among those with a history of more physically demanding jobs, more comorbid conditions, and among smokers, and are less severe among those with higher levels of education and a family history of AS.²⁹ Functional disability in AS progresses more rapidly in older patients and smokers and progresses less rapidly in those who regularly do back exercises and have better social support.³⁰ Though the progression of AS may be mild in some patients, others may experience progressive structural deterioration, pain, and functional disability. Patients may experience periods of painful, active inflammation called “flares”, and periods during which the disease is inactive known as “remissions”. Typically, for patients whose AS is progressive, symptoms become chronic and pain becomes more persistent during flares and remissions are not very long.²⁴

Quality of Life Issues:

Quality of life encompasses the net effects that a patient perceives an illness to have on his or her life. In AS, although symptoms of pain, stiffness, and fatigue are common and moderately severe, few patients develop severe functional disability and most remains employed.²

Rugiene et al. (2008) studied to understand the burden of AS, to identify the aspects of health-related quality of life (QoL) in patients with AS (n=65) and compared them with the control group (CG)(n=67).³¹ Both groups were asked to fill in the SF-36 as generic QoL instrument. QoL on all the scales of the SF-36, especially in physical

health-related QoL, was significantly worse than in the CG. Disease-specific instruments – BASFI, BASDAI, BASG and pain – were significantly associated with the component of physical and mental health related QoL. They concluded that AS influences the subjective health of the affected person; especially the physical health related QoL. BASFI, BASDAI, BASG and pain are significantly associated with SF-36 physical and mental domains in patients with AS. A. Ozgul et al. (2006) showed AS affected patients work and social life.³²

Fatigue:

In AS pain, fatigue and stiffness are the most commonly reported symptoms.^{2,33,34} In a survey of 1950 patients suffering from AS, which addressed the domain considered as the most disabling, pain was considered the predominant disabling domain by 34% of the patients, stiffness by 25% and fatigue by 6%.³⁴ Fatigue has been considered so important by some experts that it was included in a core set of variables that evaluate the symptomatic severity of the disease. For example, the Bath team of rheumatologists proposed a construct index—the Bath Ankylosing Spondylitis Disease Activity Index (BASDAI)—evaluating five domains, including fatigue (the four others are axial pain, peripheral pain, enthesiopathy pain and stiffness). In UK over 50% of the patients revealed that fatigue was the main symptom.³⁵

Sleep disturbance:

Sleep disturbance is one of the major problem in patients of AS. Night pain is strongly associated with sleep disturbance. Night pain appears to be a different entity from day pain. Disease activity (BASDAI) incompletely explains the essence of night pain. Thus other contributory factors (possibly structural involvement (BASRI) or psychological status) may play a role. Night pain does not play an important role in the occurrence of morning stiffness or fatigue. Night pain is significantly correlated with sleep disturbance and disease activity (BASDAI) and explains 65% of sleep disturbance. Disease activity (BASDAI) explains only 50% of night pain.

Psychosocial Aspects:

The psychosocial consequences of AS need extensive study to be well understood.³⁶ Because the condition is chronic, it is estimated that about 25% of patients will

develop emotional problems such as anxiety and depression. Depression tends to be more prevalent in women than men (approximately 46% vs. 26%).²⁴ Social interactions are not typically impacted to a significant extent among patients. Some women, however, report having sexual relations less frequently and with less enjoyment than women without AS. A Turkish study working with sexual dysfunction in male patients with AS showed, compared to healthy controls AS had significantly lower sexual drive, erection, problem assessment and overall satisfaction scores according to the BMSFI. Ejaculation scores were also lower but not statistically significant. According to the Beck Depression Inventory, AS patients had higher scores than healthy controls (14.9 ± 9.4 and 10.3 ± 11.8 , $P = 0.026$, respectively). The incidence rate of sexual dysfunction is higher in patients with AS, when compared to the healthy people. In patients with AS, sexual dysfunction was associated with depression and limited joint mobility.³⁷

Social Relationships:

Patients with AS should make their best effort to maintain normal social relationships and interact with a supportive social environment including family, friends, and co-workers. Most patients with AS do not experience severe illness and manage to work, raise families, and lead active fulfilling lives. One may need to make some lifestyle modifications during active inflammatory periods but these temporary flare-ups need not have an overwhelming effect on quality of relationships with friends and family members and participation in social activities. A study showed that patients with AS in this study were more likely to have never been married, more likely to be divorced, and more than twice as likely to be work disabled than members of the general population. Women with AS were also less likely to have had children than women in the general population.³⁸

Patient global assessment:

The impact of AS from the patient perspective encompasses all aspects of disease including activity, function and structural damage, in one summary measure. The ASAS group recommends the use of a single visual analogue scale measure (VAS) of global well-being "on average over the last week" as an important component of the clinical assessment. This is

consistent with the other measures in the core set, utilizing the 'in the last week' approach to obtain a snapshot of current patient status. The patient global assessment is useful in clinical practice, and may be the single most responsive measure in this setting. An alternative global measure, the Bath Ankylosing Spondylitis Global score (BAS-G) combines two VAS scores, one referring to the last week and the second to the patient's average well-being over the last 6 months, which can be helpful to describe longer-term disease progression.³⁹

Conclusion:

The principal portion of working people in Bangladesh is young male, who are more suffered from AS. The greater functional disability, cost of treatment and poor quality of life can significantly affect the entire family as well as the society. Early diagnosis, proper health education and effective treatment with affordable cost are expected to overcome this social burden in future.

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