Original Contribution

Clinical Evaluation of Ankylosing Spondylitis in Switzerland

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The purpose of this study was to identify the socioeconomic conditions and clinical history of ankylosing spondylitis patients in Switzerland.

Data collected from 1177 ankylosing spondylitis patients, through a mail-in questionnaire, was analyzed for epidemiological factors, clinical presentation, musculoskeletal related surgical history and socioeconomic impact.

The results showed that the sex ratio, average age at onset of symptoms, latent period until diagnosis, signs and symptoms, peripheral joint involvement and the prevalence of extraarticular organ affection of our patient group all conform with the majority of the published literature. Conversely, most reports suggest a higher frequency of musculoskeletal surgery, yet a lower employment capacity than the Swiss cohort. As described in other publications, aggressive physiotherapy appeared to be linked to a reduction in long-term disability, musculoskeletal deformities and surgical intervention.

It was concluded that the present cohort of ankylosing spondylitis patients underwent fewer surgeries for musculoskeletal deformities and represented a lower socioeconomic burden (relative to disability and inability to work) than most patient populations previously studied.

Keywords: ankylosing spondylitis, surgery, disability, physical therapy

From the great number of published reports on ankylosing spondylitis (AS), only a few address the frequency of surgical intervention (1,2) while the majority of studies concern the diagnosis (3-18), therapy (2,14-15,18-30,32-34), prognosis (2,14-15,18-23,25-35), epidemiology (8,13,16,18,36,37), socioeconomic effects (38-45,61), and natural history (11,46) of AS.

By using a detailed mail-in questionnaire, we determined the current situation of several disease-related aspects in a large number of Swiss AS patients and compared these data with the published literature. We had a particular interest in the incidence of surgical interventions on the musculoskeletal system as well as the degree of disability and inability to work, since these two factors are of critical socioeconomic and socio-professional significance.

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METHODS

At the time of our study in 1994, the Swiss Association of AS patients ("Schweizerische Vereinigung Morbus Bechterew", SVMB, Roentgenstrasse 22, CH-8005 Zurich, Switzerland) counted 1942 members; all of them received a detailed mail-in questionnaire. A total of 1177 patients returned a fully completed questionnaire (a return rate of 61%), supplying the data for this study.

In 33.6% of these patients, the diagnosis "AS" was made by a general medical practitioner or internist, whereas the remaining 66.4% were diagnosed by a rheumatologist.

The 50 page questionnaire included detailed inquiries concerning the patient's disease, past and present therapies, present health status, as well as personal, social and occupational data.

RESULTS

Epidemiology

The mean patient age at diagnosis was 32.5 years. The mean latent period, the time span between occurrence of first symptoms and diagnosis of the disease, was 8.1 years.

The male to female sex ratio equaled 1.9 to 1.

Clinical picture

Early morning low back pain (59% of patients), diffuse spinal pain (46%), peripheral joint pain (39%), pain deep in the buttocks (38%) and spinal stiffness (37%) were most often mentioned as early symptoms of AS in our patient group.

As the disease process progressed, the increasingly fixated hyperkyphosis of the thoracic spine became the main complaint, affecting 62.8% of our AS patients.

Peripheral joint involvement was present in 31.5% of our group. In 58% of these cases the hips, in 35% the shoulders, and in 31% the knees were affected.

Extraarticular organs were affected in almost one third (32.2%) of our patients. The organs involved included the eyes (iritis, uveitis: 26%), the intestine (diarrhea, weight loss, food intolerance, Crohn's disease, ulcerative colitis: 6%), the lungs (fibrosis, cough, dyspnea: 4%), and the kidneys (amyloidosis, IgA-nephropathy: 2.5%).

There were also unspecific symptoms affecting a substantial proportion of our patient group: fatigue (16%), difficulties with digestion (21%), abdominal cramps and pain (11%), and fever (3%).

Surgical interventions, spinal deformity, physiotherapy, and medications

Only a very small portion of our cohort (3% or 35 out of 1177 AS patients) unterwent any kind of spinal surgery. Out of the total of 40 surgical spine interventions, 21 (52.5%) involved the intervertebral disk whereas 9 (22.5%) were extension osteotomy operations to correct deformity. The lumbar spine was operated on 8 times and the cervical and thoracic spine each 3 times (more than one segment per operation possible). Hence, only 0.7% of 1177 AS patients unterwent extension osteotomy fusions. 10 intervention concerned spinal surgeries other than extension osteotomy or disk operations.

A total of 81 peripheral joint operations were performed on 69 patients (6% of cohort). Of these, 23.5% were synovectomies, 53% implantations of endoprostheses, and 23.5% were other kinds of surgical interventions on peripheral joints. In contrast to the low surgical intervention rate, 94% of our patients received formal training on AS-specific exercises, 53% of patients maintained a home exercise regimen routinely and an additional 24% intermittently performed their home program.

100% of the patients in this study were placed on targeted antiinflammatory medications at the time their diagnosis was confirmed.

Disability, ability to work

While 42.5% of the patients reported occasional working disability because of AS, only 13.2% of the cohort was permanently (but not necessarily fully) unable to work and collected a disability pension. One half (51%) of these disability pensions were partial pensions of 50% or less, the other half (49%) were more than 50% or full pensions. Only 3.3% of our cohort (39 of 1177 patients) received a full disability pension.

DISCUSSION

Calin et al. (5) showed that, although a large patient population consisting of members of an AS group may not demonstrate the full spectrum of this particular disease, it is generally representative of AS patients investigated and treated in rheumatologists' practices and hospitals.

A comparison of our results with the international literature is difficult, mainly for two reasons: First, there are very few statistical studies dealing with the frequency of AS-specific surgery, and only a paucity of investigations assess the socioeconomic and socio-professional effects of AS; second, there is no uniform use of terminology (e.g. "disability" or "inability to work"), and patient populations differ substantially in the different studies. Despite these challenges, our collective data reveals some compelling trends and may help to better understand both the disease itself and patients with AS.

The mean age at the beginning of symptoms in our group was 24.4 years. Other authors describe similar findings: Calin (5) found an average of 23.8 years, differentiating between a juvenile, an early, and a late age of onset, starting at a mean age of 13.3, 19.0 and 33.5 years, respectively. Polley (47) describes a disease onset at an average age of 26 to 27 years. Other researchers (24,48) do not report a mean age but rather a time span for first symptoms of AS to appear, ranging from 15 to 40 years.

Table. 1. Change of the mean latent perio	d
during 3 different study periods accordin	g
to McGuigan et al (41)	

Time period	Mean latent period (years)		
1956-62	approx. 9		
1969-72	7.4		
1979-82	2.3		

In our population, the latent period, calculated as the difference between mean age at the beginning of symptoms (24.4 years) and the mean age at diagnosis (32.5 years), was 8.1 years. Wordsworth (45) reported a latend period of 10.2 years in a patient population of 100. In a comparably sized patient group to our cohort, Calin et al. (5) observed that the mean latent period decreased from 9 to 2.3 years over a 26 year data collection period (table 1). They also found that the latent period is not longer in medically deprived areas of a country compared to medically well serviced areas and attributed perceived differences in latent periods (3,5,45,49) to 1) Differences in awareness concerning AS among doctors and radiologists; 2) Referral practices between general practitioners and rheumatologists. Carbone at al. (49) found a latent period of just 5 years, also noting that this time delay decreased in the last decade of their study to 3.7 years.

Concerning the sex ratio of AS patients, the literature contains many different, partially contradicting, and findings. In our cohort, the male to female sex ratio was 1.9 to 1. Earlier publications (46,50-53) describe a male predominance ranging from 15 to 1 to 4 to 1, while more recent studies (10,16,36,37,54) show a more balanced sex ratio as low as 1.8 to 1.

Different possible explanations exist for the strong male predominance of AS previously assumed. Reviewing the following information may help physicians to avoid misdiagnosing female patients with AS:

- Many physicians are reluctant to perform X-rays in the pelvic and lumbar spine areas in women of childbearing age, often ascribing their complaints to the adnexes and pelvic organs (36).
- Men are more often involved in physically demanding activities, making them more prone to consult a physician with pain and stiffness of the spine (36).
- Peripheral joints are more often affected in women with AS (6,9,12), occasionally misdiagnosed as "se-

ronegative rheumatoid arthritis" (4,37).

- AS seems to start earlier, progress faster and lead more often to spinal stiffness in men than in women (11), making it easier to diagnose the disease in men. Hill et al. (10) are talking about a sex-specific latent period, making it less than 3 years for men, but almost 10 years for women.
- Hill et al. (10) stated that the sex ratio would be 2.3 to 1 in favor of men, if, instead of waiting for the classical radiological findings to develop, a suggestive diagnosis is made based on clinical findings, blood sedimentation rate, and presence of HLA-B27.

The early symptoms of AS in our patient cohort were early morning low back pain, diffuse spinal pain, spinal stiffness, peripheral joint pain and pain deep in the buttocks. This is in accordance with studies published by other authors (7,14,48,51).

The symptoms of late disease, such as hyperkyphosis and spinal stiffening, and the resulting complications such as pathological fractures and reduced thorax mobility with impaired pulmonary function do not allow a comparison with other reports because, to our knowledge, no prior studies investigated the development of hyperkyphosis in AS.

We found a peripheral joint involvement of 31.5% in our cohort. Emery et al. (55) describe a prevalence of shoulder joint involvement of 33%, substantially higher than our 11%, although the average age in their population was also higher than ours. Hehne et al. (24) found a much higher peripheral joint rate than we did (43% compared to 31.5% in our cohort), however, men, who generally demonstrate more spinal symptoms but fewer peripheral joint complaints, were strongly overrepresentated (87%) in their sample.

The prevalence of extraarticular manifestations of AS in our study group is in accordance with the literature (19,21,24,56,59,60,62-64), both concerning the kind of organs affected as well as their frequency.

Vague symptoms, a long latent period, a lag of radiological involvement, and a negative HLA-B27 may all lead to a delay in diagnosing this sometimes elusive disease process. This enigmatic nature of AS is most notable in women, who seldom develop classic radiological findings and whose clinical presentation differs somewhat from that of men affected by AS.

We consider the incidence for operations on the spinal

Author(s)	Time period	No. of Operations
Hehne and Zielke (24)	3-4 years	100
Simmons (30,65)	24 years	330
Halm, et al (22,23)	9 years	200
Weale, et al (34)	NA	50
Van-Royen and Slot (31)	NA	20
NA: Not applicable		

Table. 2. Some publications investigating spinal erection operations (extension osteotomies) in AS patients

column to be very low in our group (barely 3%). Operations to correct spinal deformity were performed in only 0.7% of the total number of AS patients (9 persons).

To our knowledge, precise figures for the number of straightening operations (extension osteotomy) per 100 patient years in large AS populations have never been published, except for one study by Koh et al. (2). In their investigation an prevalence of 0.5% is given for cervical spine operations in a cross-sectional study of 3464 AS patients.

Hehne et al. (24) state that extension osteotomy operations were performed on at least 100 patients during a 3 to 4 year period (1983-1986). Simmons (65) was involved in 330 such operations over a period of 24 years (table 2). Although we know of no large cross-sectional studies that have examined the incidence of lumbar/thoracic extension osteotomies in AS patients, the number in our cohort seems to be very low, and we offer two possible explanations for this assumption:

- With the prevalence of AS being at least 0.15% according to Gran et al. (8), and with the prevalence of extension osteotomies in our group being 0.7%, this would translate into 600 operations for (former West) Germany with its approx. 60 Mio. citizens. Since the group around Zielke (22-24) alone was involved in more than 300 such operations, it must be assumed that the prevalence of extension osteotomies in Germany is much higher than 0.7%.
- Koh et al. (2) report a frequency of 0.5% for cervical extension operations in their cross-sectional U.S. study. Since lumbar/thoracic extension operations are performed much more frequently, the total prevalence of spinal extension osteotomies in the U.S. must be – based on Koh's data – far beyond the 0.7% that found

in Switzerland.

We consider different possible explanations for this low number of spinal extension operations in this cohort of Swiss AS patients:

A large portion of our patients received regular physiotherapy (figure 1). 53% of all patients reported having physiotherapy or doing independent exercises on a regular basis, and another 24% do so occasionally. However, active use is also made both of intensive inpatient therapy in health resorts and of regular AS group therapy.

The correlation between intensive mobilizing exercises or therapy and increased spinal flexibility and reduced kyphosis has been examined closely and confirmed by various authors (20,25,27-29,33,66). The main reason for extension operations is not a stiff spine as such but the presence of fixed kyphosis (usually over 40 degrees) of the thoracic spine. A markedly flexed position of the upper body restricts both the field of vision and lung function (24,63,65). Furthermore, the ensuing feeling of social rejection is intensified and the degree of individual suffering is vastly increased, ultimately leading the patient to seek a surgical solution.

The assumption, previously considered obvious, that hyperkyphosis of the spine is an unavoidable and general tardive sequela of AS, is seriously contested by a discovery by Simmons et al. (30)in 1991. In their report, Simmons et al. describe the significance of muscle pathology in the development of flexion deformity in AS patients.

The question – whether an insufficiency of the erector spinae muscle in AS patients with hyperkyphosis is



the consequence or the cause of the latter – is a crucial one. If it is the cause, then treatment aimed at restoring muscle strength would be extremely important in preventing the development of fixed kyphotic deformity, and the intensive use of exercises and physiotherapy in our group could – at least in part – explain the low incidence of this condition in the Swiss cohort.

Some studies suggest that early, targeted and, if necessary, aggressive anti-inflammatory medication may mitigate the development of hyperkyphosis (4,46). Apart from intensive physiotherapy, anti-inflammatory medication forms an integral part of the conservative therapy of AS in Switzerland; one hundred percent of the patients in the present cohort were provided with such a regimen from the time their diagnosis was es-

tablished.

Commensurate with the low number of spinal surgeries, the prevalence of operations on peripheral joints in our cohort is 6%. There are studies describing the prevalence of shoulder conditions in AS, citing figures from 30 to 80%. However, to our knowledge, there have been no publications on the prevalence (or incidence) of operations on peripheral joints in patients with AS.

While 13.5% of our AS patients receive a disability pension, only 25% of these are full pensions, which corresponds to 3.3% of the entire cohort. This result is in sharp contrast to other authors describing substantially higher disability rates (18% in (45), 30% in (67), 36% in (68)). This discrepancy is still striking, even if all recipients of

Table. 3. Comparison of the findings of different studies concerning disability, disability pension, and ability to work in AS patients

Study	Full disability	Disability pension	Ability to work
Present study	3.3%	13.5%	96.7%
Smukler (17)	2.7%	NA	97.3%
Schwenk (44)	NA	36%	100%
Wordsworth and Mowat (45)	NA	18%	93%
McGuigan et al (41)	NA	NA	93%
Schramm et al (43)	NA	51%	NA
NA: Not applicable			

disability pensions in our cohort (13.5%) were considered recipients of full disability pensions.

Concerning the socioeconomic significance of AS, a clear distinction between working ability (ability to work), receiving a disability pension (partial or full), and full disability (being unable to work and care for oneself) has to be made (table 3). The comparative results of studies using any of these terms must be interpreted with caution for several reasons:

- There is an over-representation of individuals with severe impairments in studies describing cohorts of hospital or clinic patients. On the other hand, one could speculate that a study based on mail-in questionnaires over-represents younger and "healthier" patients, as they are living at home and are able to participate in such a study.
- Terms such as "physical complaints", "functional limitations", "working ability", "physically demanding professions", and "elderly" are all difficult to define and quantify. Studies examining such broad variables lead to results that can, at best, be interpreted as "tendencies" and a comparison of such studies must consider the exact circumstances under which such data was collected.
- The ability to work is not only dependent on the health of the patient, but also on the unemployment rate, job market structure, and the availability (and accessibility) of retraining programs. These factors may differ greatly from one study to another that objective comparisons are nearly impossible.
- Some study populations contain substantial portions of people working in physically demanding jobs 50% (68), 60% (67), 80% (43)). In our cohort, this ratio was relatively low (30%). This is one of the reasons why extreme differences in job-specific working abilities in the different studies are inevitable and difficult to compare.

Despite these inherent difficulties, some basic concepts about disability and working ability in AS patients are possible and were, in part, confirmed by our findings:

- The degree of disability does not depend on the duration of the disease or the degree of peripheral joint affection (40,45,68).
- Patients with physically demanding jobs may have a higher risk of disability (39,43,68). This is supported by the fact that studies with a high percentage of patients active in physically demanding professions con-

sistently show higher disability rates.

- Consistent physical therapy and/or specific exercises are the pillar of conservative non-drug treatment of AS (18,25-27,32,33,43,69). Our study suggests that this may even reduce disability, fixed kyphosis, and the need for spinal surgery.
- Disability is more common in patients with early disease onset, who were active in nonsedentary professions at the time of onset and who lack the possibility to retrain for another job activity (12,42-44,68).

These observations engender the need for early recognition and diagnosis, aggressive physical therapy and drug treatment, job counselling for young patients, job retraining for those with physically demanding occupations and psychosocial support.

CONCLUSION

The present cohort of AS patients underwent fewer surgeries for musculoskeletal deformities and represented a lower socioeconomic burden from disability and inability to work than most patient populations previously studied. The low incidence of patients requiring surgery to correct fixed spinal flexion deformity in our study group suggests that severe and disabling hyperkyphosis is not an inevitable consequence of AS. Physiotherapy and anti-inflammatory medications may play a cardinal role in retarding AS related spinal inflexibility and hyperkyphosis, thereby reducing the need for surgical correction.

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