

Everyone Has the Right to Work



Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment.

— Article 23.1, Universal Declaration of Human Rights (1948)

The impact of rheumatologic conditions on the ability to perform paid work is well recognized and is a continuing focus of research and debate. As early as 1969, Steinbrocker reviewed the employability of patients with arthritis in the United States¹. Based on a study of the Public Health Service, he reported that activity limitations occurred annually in 26% of subjects with arthritis and that 10% were completely work disabled. In the same article, he expressed his regret that in the report “arthritic disabilities were not separated into the specific articular diagnoses.” He continued his overview with data supporting different prognoses of employability in patients with rheumatoid arthritis (RA), osteoarthritis, and gout.

In this issue of *The Journal*, Dr. Mau and colleagues compare employment across 6 inflammatory rheumatic diseases in Germany and explore variables associated with reduced employment². The publication is of interest for at least 2 reasons. First, because only a few studies have directly compared different rheumatic conditions. Second, because they identified the influence of labor market conditions, in addition to education level, on employability. The conclusions are based on self-reported employment of a large number of patients ($n = 43,466$) who were between 20 and 65 years when they were included into the National Database of the German Collaborative Arthritis Centers in the period 1993 to 2001. Nearly 60% of the patients were diagnosed with RA ($n = 26,071$) and 35% of patients with either ankylosing spondylitis (AS; $n = 5564$), psoriatic arthritis (PsA; $n = 6041$), or systemic lupus erythematosus (SLE; $n = 4603$). A further 802 patients had systemic sclerosis (SSc) and 385 Wegener’s granulomatosis. The large number of patients is necessary to calculate standardized employment ratios (SER).

Standardization is a prerequisite when comparing work related outcomes between diseases due to the large differences in age and sex distribution between patient groups and the general population. Among Dutch patients with AS in The Netherlands, raw data showed an employment rate of 62.9%, which was only 1.3% lower than in the general population, while after indirect standardization for age and sex the SER was 0.82, resulting in an adjusted employment of 54.4%, 10.8% lower than in the population³.

In addition to standardization for age and sex, Mau, *et al* also adjusted for education level and for time of inclusion into the database. Since patients were included in the database between 1993 and 2001, it should be realized the SER are actually average standardized ratios over that period. Although the importance of standardization seems obvious, it is striking that few studies in the rheumatological literature have presented standardized ratios or adjusted rates³⁻⁵. If it is accepted that the benchmark for work related outcome is the general population, standardization for at least age and sex is a prerequisite for correct interpretation of work related outcome. In the present study, the authors presented in a second analysis the SER of each disease as compared with RA as the reference. This provides a more direct illustration of the differential effect of the conditions on employment. It must be recognized that the choice of RA as the reference is purely subjective.

Standardization is not a difficult technique, but the requirement of population data on work related outcome for several age categories and both sexes separately can be a limiting factor. In addition, identical definitions of outcome (especially outcomes describing work disability) as well as comparability of included subjects as the background population are often less straightforward than one might assume. The choice of Mau, *et al* to study employment as the sole work related outcome might have been motivated by the difficulty to retrieve the detailed population data on work disability necessary for indirect standardization. One wonders, however, whether employment reflects the full impact of disease on work participation. Outcomes describ-

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ing the causes of disease related non-employment such as official work disability, economic unemployment, early retirement, etc., improve insight into the full work perspectives of the patients.

DIFFERENCES AND SIMILARITIES IN EMPLOYMENT BETWEEN DISEASES

Differences can be seen when comparing work participation between diseases. Overall, RA and SSc had a more profound effect on work participation, and RA was the only condition in which work participation was already reduced in the first 5 years after diagnosis. Another clear difference among diseases was seen in AS, where female patients had better (and even normal) employability compared to male patients, while in other conditions employment tended to be more reduced among females. Better and normal female employability in AS was already reported in an earlier study and attributed to the small sample size among the women in that study³. This argument cannot be applied to the present study, which includes 1800 female patients with AS.

Although we are tempted to explain the observed differences, we should realize that employment is a complex outcome (Figure 1) and the present study was not designed to identify such explanatory variables. Indeed, more similarities than differences were noted across diseases: In all conditions SER decreased with increasing disease duration,

indicating that difficulties in remaining employed become more pronounced over time, also when adjusting for increasing age. These figures should be interpreted in the correct perspective with regard to the relative contribution of disease duration and age. The incidence of withdrawal from work according to the age of the patients in comparison with the general population [or the standardized incidence rates (SIR) of withdrawal] could provide a different view. In AS it was shown by calculating SIR that the younger patients were at the highest risk for withdrawal from work when compared with sex and age matched subjects from the general population⁶.

Within all the rheumatologic conditions, the effect of education on work participation was striking, and overall, patients with less than 9 years of formal education were 1.5 times more likely not to be employed. The adverse effect of lower education in RA and AS has been confirmed in several but not all studies examining this relationship⁷⁻⁹. All the studies looked at the impact of education level on employment within patients. However, it is known that in the general population as well education influences work participation. The present study clearly shows that in patients the effect of education is amplified when compared with its effect in the general population. Interestingly, while in female patients with AS overall standardized employment was not decreased, in the subgroup with low education

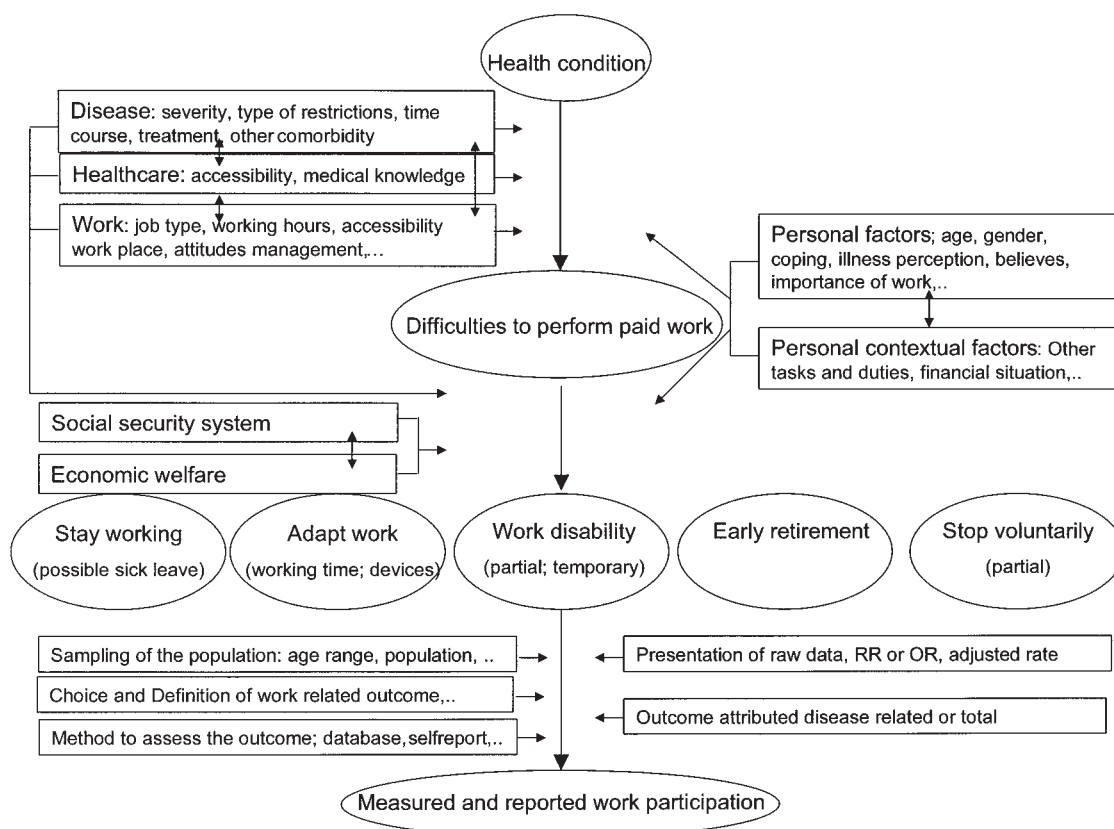


Figure 1. Variables likely influencing work related outcome as reported in studies and surveys.

employment perspectives were less favorable. As discussed by the authors, education level is a surrogate for many other variables such as type of job, access to healthcare, self-management skills, and attitudes of health professionals.

The present observation calls for a precise and generalizable definition of education and for further research into the relevant constituents of education and their relationship with outcome¹⁰.

RELEVANT REGIONAL DIFFERENCES IN EMPLOYMENT RATIOS

Much attention is devoted to differences in employment ratios between the old and new federal states in Germany. The unification in 1989 of 2 nations with very different political and economic systems, the one having a free market and the other a state controlled economy, offered a unique opportunity to assess the influence of the socioeconomic environment on employment.

Overall, patients in the new federal German states (NFS), were 1.47 times more likely not to be employed when compared to patients in the old federal states (OFS), after adjusting for differences in employment and education level versus the general population. Reduced employment in states with a formerly state controlled economy was consistently observed among rheumatologic conditions and for both sexes. The differences are attributed by the authors to the large differences in unemployment rates, which were, between 1993 and 2001, continuously higher in the NFS (varying from 14% to 18%) compared with the OFS (varying from 9% to 11%). However, other reasons for differences in employment can similarly be considered. When the database started in 1993, it was a cross-sectional sample, and these patients make up about 50% of the present study group. A substantial proportion (specifically those with disease duration of more than 10 years) was diagnosed before unification and some likely had left the labor force in the socioeconomic environment of the original regime. Not only the labor market conditions but other factors, such as social security system as well as access and availability of healthcare, can explain differences in work related outcome.

With these considerations in mind, it should be noted that the largest differences in employment ratios between the old and new federal states are seen in RA, SLE, and SSc. For these conditions it is well known that in the last decade the prognosis was positively influenced by more intensive treatment approaches. Since it is unlikely that after the unification of Germany the organization and provision of healthcare equalized immediately, it cannot be assumed that this form of left censorship — inclusion of patients with a different severity of the disease in both regions — can be ignored. The authors argue that disease severity did not differ between patients of the new and old states. However, disease severity was assessed by physician global assessment on a 1 to 5 scale (asymptomatic to very severe). The physi-

cian assessment likely adopts a “median” disease severity of all patients under a physician’s care as the benchmark to rate the disease severity of the individual patient, and this “median severity” might differ importantly between the 2 regions.

A recent publication on labor force participation among patients with RA in Lithuania, one of the Baltic countries that gained independence from the Soviet Union in 1990, looked at the influence of the year of transition to a free market economy on employment in a time-dependent Cox regression analysis¹¹. Patients diagnosed after 1990 were 2.75 times (95% CI 1.60 to 4.53) more likely to become (officially) work disabled. During the same period unemployment increased 1.5 times, confirming the influence of labor market conditions on employability in RA. However, the authors also mentioned that after the political transition the state resources for social security and healthcare were reduced, so unfavorable changes in disease severity in the same period could have influenced work participation.

The importance of the socioeconomic environment on employability was confirmed in patients with AS in a European study in 3 countries assumed to have equal standards of healthcare. The human capital costs, reflecting mainly costs due to work disability, were 2.17 (95% CI 1.47–3.13) times higher in The Netherlands compared with France and Belgium after adjusting for education level and disease severity¹². Remarkably, lower unemployment but higher work disability rates were noted in The Netherlands compared with both other countries. The role of a more favorable social security system with higher disability pensions in The Netherlands was discussed. Therefore, although several studies now clearly point to its influence on employment perspectives, the socioeconomic environment seems to represent more than labor market conditions only. It is a complex surrogate also reflecting the healthcare system and consequently health, type of available jobs, working conditions, social security organization, and attitudes towards work.

Notwithstanding, the article by Mau, *et al* emphasizes that work related outcomes are not the universal “hard outcomes” as sometimes suggested, but are influenced by a great number of contextual factors (Figure 1), including socioeconomic factors. The latter issue is especially relevant in economic analyses, where international transferability of cost-effectiveness data that include indirect costs is an issue.

Unemployment data from the countries of the Organization for Economic Cooperation and Development (OECD) illustrate the large variation in unemployment across these countries. In 2001, for example, in Europe, standardized unemployment was 2.1% in Austria (lowest), 8.4% in France, and 19.4% in Poland (highest)¹³. Considering the findings of Mau and colleagues, the impact on work related outcome in the chronically ill is expected to be important.

What can the clinician learn from this interesting study?

With the adoption by the World Health Organization of the framework of the International Classification of Functioning, Disability and Health (ICF), the medical profession accepts that its responsibility to the patients extends beyond control of disease activity and severity. Insight into all relevant factors (including the socioeconomic environment) that contribute to the comprehensive functioning of patients will improve our care for the individual patient and strengthen our position in discussions on healthcare reforms and when setting priorities for research.

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